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# A PHENOMENOLOGICAL DESCRIPTION OF THE LIVED EXPERIENCE OF CREATING ART FOR WOMEN WITH BREAST CANCER

by

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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Department of Nursing in the College of Nursing at the University of Central Florida Orlando, Florida

Summer Term 2010

Major Professor: Angeline Bushy



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#### **ABSTRACT**

Conventional approaches to cancer treatment typically do not address the personal experiences of the women with breast cancer. The aim of this study was to develop a structural description of the lived experience of women with breast cancer who create art, specifically through painting, sketching or drawing.

A phenomenological approach was employed to explore the meaning of creating art for four women with a diagnosis of breast cancer. The philosophical underpinnings for this study were based on the phenomenological method of bracketing which allows the researcher and subjects to focus on lived experience. This qualitative methodology provided a means to examine the phenomenon of interest in depth from the participants' subjective perspective. Data were collected through face-to-face interviews and follow up telephone conversations. Giorgi's method for analyzing phenomenological data was used to elicit an invariant description of the meaning that creating art had for the participants.

Three predominate themes emerged from the analysis. Contextual constituents of the phenomenon were identified as that of giving back and time to create. Dynamic components consisted of creative space and creative expression. Enduring factors consisted of the creative experience and sense of self. Nurses are in a unique position to facilitate the creative art process which holds the potential for self-healing and self-responsibility for their patients. Included are limitations of the study and recommendations for future research.



This study is dedicated to every woman who has heard the life-changing words, "You have breast cancer." May this work provide you, your loved ones, the nurses and physicians who care for you with an additional option for dealing with the aftermath of this disease.

For the women in this study who said, "Yes" to participating in this research project. For my sister, Lei Ann, whose valiant battle with breast cancer and a drawing of a red house on notebook paper planted the seed for this dissertation. For my sister, Joey, whose work with watercolor with women receiving chemotherapy for breast cancer germinated the seed. For my sister, Amy, who did much to keep the idea alive when the sun didn't shine. For my parents, Ron and Joan, who have always believed in me. For my husband, Steve, without whom this journey would not have been possible. For our son, Andrew, whose keen mind keeps me energized. For his lovely bride-to-be, Jackie, who has been with me through the many ups and downs. Most especially, for our daughter Sarah, whose passion for art has opened my eyes to many of the possibilities of healing through creativity.



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# CHAPTER 1 THE PROBLEM AND ITS CLARIFYING COMPONENTS

#### Introduction

Florence Nightingale, considered by many to be the very first nurse researcher, noted in 1859 the possible positive effect on patients' recovery from illness through the use of "fancy' (Nightingale, 1980). She wrote: "Little as we know about the way in which we are affected by form, by color, by light, we do know this, that they have an actual physical effect" (p. 46). Since that time there has been little research carried out by nurses who believe, as did Florence Nightingale, that there is a decided effect on patients who create art or who are exposed to some form of artistic expression. The focus of this study is to explore whether, or not, such a response does exist and how that experience is described by a specific population.

#### Background of the Study

The manner in which nurses provide care for their patients has changed since Nightingale's time. Yet nurses continue to render treatment for patients burdened with similar conditions, in particular, breast cancer. With the exception of skin cancer, breast cancer is the most common cancer among American women (American Cancer Society, 2009). The chance of developing invasive breast cancer at some time in a woman's life is about one in eight. In 2000, there were an estimated 2.5 million breast cancer survivors who are women in the United States (Zebrack, 2000). From 1996 to 2004 the five year survival rate for women with breast cancer was 88.7% (National Cancer Institute, 2009).



In 2005, the most recent year for which statistics are available, 184,467 women were diagnosed with breast cancer in the U.S. (Centers for Disease Control, 2009).

Breast cancer may be one of the oldest ailments shared by women across the ages. Breast cancer was as well known to women of ancient times as it has been to those living in the 21<sup>st</sup> century (Olson, 2002). Documentation of removal of the breast for the treatment of cancer dates back to the 3<sup>rd</sup> century when Saint Agatha, patron saint of breast disease had both breasts removed (Thorne & Murray, 2000). In the 1880s, a prominent surgeon at Johns Hopkins University, by the name of Halstead, advocated for the removal of lymph nodes, surrounding tissue and muscles of the chest wall when removing the breast for the treatment of breast cancer (Batt, 1994). By the 1970s, women had begun to question the standard of one approach fits all treatment for breast cancer and challenged physicians to provide other treatment options (Lerner, 2001). Until recently, the radical mastectomy remained the treatment of choice for women diagnosed with breast cancer. Research on the efficacy of less invasive breast cancer treatment options such as radiotherapy, chemotherapy, immunotherapy and hormonal therapy has been slow to evolve (Henderson, 1995). Other than the addition of hormonal therapy, cancer therapies available to women with breast cancer in 2009 are essentially the same options that have been available for the past 50 years: surgery, radiation and chemotherapy.

Conventional approaches to breast cancer treatment do not address the subjective experiences of the women with breast cancer. Early research sought to develop coping strategies to address the uncertainty experienced by women with breast cancer (Hilton, 1988). Moreover, exploration of the experiences of women living with cancer exposed



the inadequacy of disease treatment modalities for breast cancer. Fear of recurrence was identified as a major aspect of adjusting to living with a diagnosis of breast cancer for women (Fredette, 1995). Subsequently, research sought to address the gap in understanding the uncertainty of having breast cancer and what that experience meant for women with the disease (Nelson, 1996). When addressing the healthcare needs of women with breast cancer, Colyer (1996) found a deficit in the holistic approach in attending to their needs. Another study showed that women have an increased awareness of their lives and the possibility of their death as a result of living with breast cancer (Arman & Rehnsfeldt, 2002).

The findings of research that further explored women's experience with breast cancer, suggested spirituality was found to be useful in helping a group of women cope with the disease and the treatment (Bussing, Ostermann, & Matthiessen, 2007; Schneider, 2007). In addition to the support received through their religious beliefs, another group of women coping with breast cancer were helped by acceptance and distraction (Lauver, Connolly-Nelson, & Vang, 2007).

Early detection and successful treatments have been credited with the potential for long-term survival of breast cancer for women; consequently an interest in enhancing survivorship has emerged. The American Holistic Nurses Association was founded in 1981 with the primary objective of bridging traditional medical treatment modalities with complementary and alternative healing practices within the context of nursing (Helms, 2006). Of all members of health care teams, nurses are in a central position to assess the needs of and educate patients about options for adjuvant activities. As Complementary



and Alternative Medicine (CAM) has been integrated into conventional medicine, nurses are in ideal positions to facilitate the self-healing and self-responsibility properties of CAM therapies for their patients (Denner, 2007).

Complementary and Alternative Medicine (CAM) encompass a broad range of therapies, outside of traditional medical practices. CAM interventions have been gaining international acceptance for the healing properties those options offer for the treatment of a variety of human conditions (National Center of Complementary and Alternative Medicine, 2009). A study of patients with a variety of cancer diagnoses found an individual's immune system was enhanced with CAM (Humpel & Jones, 2006). Women with breast cancer have been shown to use CAM more often than do individuals with other types of cancer (Morris, Johnson, Homer, & Walts, 2000). In 2005, 81.9% of women diagnosed with breast cancer reported using a CAM product or participated in a CAM practice compared to only 66.7% percent in1998 (Boon, Olatunde, & Zick, 2007). Many patients use CAM in an effort to deal with the undesirable side effects of conventional breast cancer therapies (Jacobson, Workman, & Kronenberg, 2000).

The list of CAM therapies has expanded as researchers have discovered interventions that are safe and effective healing practices. The National Center for Complementary and Alternative Medicine (NCCAM) has categorized CAM healing practices into four domains: Biologically based practices use substances found in nature such as herbs, foods and vitamins. Energy therapies involve the use of energy fields. Manipulative based practices focus on manipulation or movement of one or more parts of the body. Mind-body interventions enhance the mind's capacity to have a positive effect



on physiological functions as well as to provide relief from symptoms of illness. Mindbody CAM incorporates the use of creative outlets such as art, music or dance.

This researcher's initial interest in the lived experience of women with breast cancer who participate in the mind-body CAM of creating art was piqued when her sister, an artist as well as a baccalaureate prepared nurse, began to instruct women in water color painting while they were receiving chemotherapy for breast cancer (J. Haderer, RN, BSN., personal communication, October 11, 2005). Haderer's conviction and anecdotal reports that the experience of creating art was responsible for initiating profound physical and emotional changes in these women was compelling.

Of the photographs taken during these painting sessions, two were especially descriptive of the experience. One of the photographs showed a woman named Ginny intently concentrating on the process of creating a piece of art with watercolor on paper while receiving a chemotherapy treatment. Haderer, who was facilitating the creative art experience, was nearby to answer questions and to assist in the painting, but the experience was Ginny's.

Research suggests that the right side of the brain is superior to that of the left side at perceiving emotional expression and mood (Bowers, Bauer, Coslett, & Heilman, 1985; Tompkins & Mateer, 1985). The brain responds to the image of a thought or an idea before it reacts to the words that describe that thought or idea (Ganim, 1999). In allowing an image to enter the right side of the brain while viewing the photograph of Ginny and her finished painting, the mind is filled with the possible descriptors that Ginny may have used to describe this experience.



Viewing the pictures of Ginny led this researcher to further reflect on the phenomenon. When given the opportunity, how could Ginny describe her experience of creating art after a diagnosis of breast cancer? What, if any, benefit did Ginny receive from the creative art experience? Ginny's narrative had the potential for providing a description of the effect of creative expression for women with breast cancer.

Ginny's account of her creative art experience, coupled with that of other women who create art after a diagnosis of breast cancer, holds great promise for enhancing knowledge about the benefits of mind-body CAM for this population. Likewise, there exists a potential benefit for patients diagnosed with other medical conditions as well. Describing the lived experience of creating art for women after a diagnosis of breast cancer seemed to be a logical first step toward understanding the phenomenon. Consideration was given to whether the experience of creating art would be described differently by women who created art prior to the diagnosis of breast cancer when compared to those women who began to explore creative expression after a diagnosis of breast cancer. Additionally, how would the description of creating art aid in providing a better understanding of the role of health care in facilitating the creative art experience?

During this time, another of the researcher's sisters was dealing with a recurrence of breast cancer. A drawing sent to the researcher by her provided further incentive to investigate the lived experiences of women with breast cancer who create art. The drawing, which was a simple crayon rendering of a red house with smoke curling from the chimney and a path leading to the front door, led to a number of questions regarding the rationale and purpose of the piece. For instance: What was the extent to which the



lived experience was depicted in that creative artistic expression for the woman who had created the drawing? Was there a rationale for creating this particular piece? Was the purpose for making the drawing to express a thought or a feeling through a medium other than speech? At this juncture the researcher became committed to understanding the meaning of the experience of creating art for women with a diagnosis of breast cancer.

These questions served as the impetus to explore the phenomenon in greater depth.

Supporting doctoral course work was completed by the researcher in the Arts in Medicine (AIM) Summer Intensive program at Shands Hospital in Gainesville, Florida. During that time, the researcher was introduced to the historical and philosophical foundations of the AIM program. She was also given the opportunity to explore various artistic modalities and to work with patients. Ranging from children to the elderly, as well as having a variety of diagnoses, the patients explored artistic expression in a multitude of mediums of their choice. Providing art materials for the patients to use and visiting with them while they created their art work led to further questions about the lived experience for each of these individuals who were creating art while dealing with health issues.

Mary Rockwood Lane, a nurse researcher has been a pioneer in the area of the nurse's role in facilitating the creative art experience with patients. Lane's research has explored the effect of art on patients, the artists that facilitated the art experiences, healthcare providers as well as the families of the patients (Lane, 2005; Lane & Pole, 1994). Her goal has been to illuminate the process by which art heals so nurses can learn about the powerful healing potential that creative art holds for their patients.



Lane continues to be instrumental in contributing to the body of knowledge that frames the creativity and spirituality of the healing arts. She has overcome the concerns voiced by some skeptics about art experiences only being facilitated by a trained art therapist. She asserts that there is a vast difference between art therapy and its goal of providing psychotherapy and that of providing an art experience for the purpose of healing. Healing art allows the patient to find meaning and transcendence in their illness through the creation of art (M.R. Lane, personal communication, April 12, 2006).

#### Purpose of the Study

The purpose of this dissertation was to develop a structural description of the lived experience of women with breast cancer who create art. The specific focus of the study was to describe the lived experience of women with breast cancer who create art by painting, sketching or drawing.

#### Research Aim

The aim of this dissertation was to investigate the lived experience of women with breast cancer who create art. Meaning in life refers to the value and purpose one experiences in their life (Fife, 1994). Of necessity, then, the findings of this research were based on the description of the life-worlds of each of the study participants. The focus on the life-world, or lived experience, of the women provided a description of creating art after a diagnosis of breast cancer. Each woman was asked to provide, as fully as possible, the story of the phenomenon. This involved obtaining data through the women's'



responses to open-ended questions rather than asking the research subjects to pre-defined questions. The events of the lived experience, the "before" and the 'after", each woman's thoughts, feelings and behaviors contribute to the meaning for each study participant.

#### Method of Inquiry

Collie and Long (2005) have argued that in order to create conditions that are conducive to "meaning making" for women with breast cancer, it is critical for the clinician to allow for whatever expression the woman chooses to have. The phenomenological approach was employed to describe the meaning and meaning making of creating art for a group of women with breast cancer.

As a qualitative research method, phenomenology provides an avenue for direct exploration that seeks to describe a particular phenomenon or experience, as free from unexamined presuppositions as possible (Spiegelberg, 1975). In this dissertation, this approach provided for examination by the researcher of the typical structures or "essences" of each woman's lived experience of creating art with breast cancer and the relationships among those descriptors. Additional attention was focused on the ways the phenomenon presented or occurred within the context of creating art for the study participants.

Each individual, in her everyday life, brings a distinctive variety of values, ideas and biases to the interaction with the researcher. Some dimensions of this lived experience are unique to the individual while others are common to others with whom a commonality is shared (Luft, 1998; Paley, 1997). Within phenomenology, this "natural



attitude" is not only an awareness of one's immediate surroundings and an overall way of being but also extends beyond the immediate field of experience of the individual (Russell, 2006).

Described in more detail later in this dissertation, a series of specific steps of phenomenology were carried out to provide an in depth description of the lived experience of creating art for the study participants. More than providing a mere description of the phenomenon, through the use of the phenomenological method, the researcher sought to provide the essential and invariant structures that describe the lived experience of the women in this study.

### Significance of the Research

The art of nursing entails more than the mere assessment of vital signs and the review of laboratory values. Rather, an aesthetic knowing allows for a more holistic approach to nursing care. This artful caring incorporates the many facets of nursing science, aesthetics, as well as the incorporation of the ethical/moral self (Carper, 1978, 1979). Watson (2005) adds spiritual, transpersonal and caritas (caring) to the list of attributes that are necessary for nurses to possess this knowing. The findings of this research can offer insights about the creative art experience for women who have had breast cancer. This understanding can inform nurses about healing interventions that transcend conventional medicine. The findings of this study have the potential to contribute to (a) nursing practice, (b) nursing education, and (c) nursing research.



At the time of this study, there was a paucity of research that described the lived experience for women with breast cancer who create art. The personal accounts of the women in this dissertation are deemed important in aiding a better understanding of the benefits of creating art. The description of the lived experience of creating art they provide will give insight into the phenomenon, identify the associated attributes and establish a foundation for future research on the phenomenon.

Upon receiving a diagnosis of breast cancer, women who indicate a preference for active involvement in planning their treatment have shown greater psychological adjustment than do their counterparts with passive treatment involvement (Hack & Degner, 1999). Improved psychological adjustment to breast cancer has been found among women whose response to the diagnosis and treatment was fostered by behavioral coping such as logical analysis, social support, problem solving and a positive sense of well-being (Hack & Degner, 2004).

Promoting adjustment in women with breast cancer (Stanton, et al., 2005) as well as understanding the ways individuals respond to the stress of breast cancer has been shown to be enhanced by the integration of experimental as well as self-care strategies (Glinder, Beckjord, Kaiser, & Compas, 2007). Research continues to suggest the psychosocial needs of women with advanced breast cancer are different from those of individuals diagnosed with other types of cancer (Aranda, et al., 2005; Vilhauer, 2008).

While surgery performed in 2010 for the treatment of breast cancer is less likely to cause the physical deformity that resulted for women in the 1950s, mastectomy has continued to be responsible for a negative impact on a woman's body image (Pelusi,



2006). In another study of women dealing with a recurrence of breast cancer, researchers found the factors contributing to sexual disruption for this group of women were unknown (Andersen, Carpenter, Yang, & Shapiro, 2007). The need for further investigation into strategies for helping this population of women to maintain quality of life in regard to their sexuality was stressed.

Research into body image, sexual roles and emotional reactions was conducted with women who underwent prophylactic bilateral mastectomy (Brandberg et al., 2008). The researchers did not find a correlation between the surgical removal of women's breasts and anxiety, depression, or quality of life. The data did, however, suggest a negative impact on sexuality and body image.

#### Organization of the Dissertation

This first chapter provided an introduction to the study, its purpose and design components. Chapter two provides a review of the relevant literature beginning with the evolution of art as a healing modality, art therapy as a profession, research conducted by art therapists and a variety of other disciplines including nurses on the effect of art for their patients. Chapter three examines the key elements of phenomenology in the style of Husserl and the evolution of this study in particular. The methodology used to conduct the research and the research design was included. Chapter four describes the study participants and presents an analysis of the data. The concluding chapter provides a discussion of the interpretation of the results, the strengths and weaknesses of the study, and implication for nursing practice, nursing education, and nursing research.



# CHAPTER 2 REVIEW OF RELEVANT LITERATURE

#### Introduction

This chapter presents a literature review the focus of which was on the use of art as an adjuvant treatment option. Apart from the use of art as a psychoanalytic technique, the literature describes an emergence of the use of art as an adjunct therapy to traditionally Western healthcare treatment modalities. The following describes the evolution of art therapy from a psychotherapeutic technique to a multidisciplinary adjuvant therapy is considered. In an effort to remain true to the assumptions of phenomenology, which require the researcher to remain without presumption, the extensive review of the literature was delayed until after the data in this dissertation were analyzed.

The struggle to understand the efficacy of art within a modern healthcare framework suggests that insight about the experience of creating art for a specific sample population is needed. The healing benefits of artistic expression are explored from a historical perspective as well as from a treatment option. While current nursing research lends scientific support for the benefits of incorporating art into the healthcare plan for a variety of patient populations only two studies were located that describe the effect of artistic expression for women with breast cancer (Ponto, 2003; Predeger, 1996). Of them, only one study sought to describe the experience of the participants (Predeger, 1996). This, thereby, reinforces the information gap on this particular phenomenon.



### The Evolution of Art as a Healing Modality

Samuels and Lane (1998) suggest the earliest form of healing art existed within the context of a woman singing a lullaby to a babe in arms. Anyone who has ever sung such a song or observed the action can appreciate the soothing ministration that takes place between the two involved in the event. Among the literature that abounds with stories and testimonies of the effect of art on healing is the Bible. The Old Testament finds Saul filled with depression and fear. A young man by the name of David is summoned to play the harp to quiet Saul and return him to good health (1 Samuel, 16:11). Indeed, it would appear that the healing effect of art can be traced back to the beginning of mankind.

#### Art Therapy as a Profession

During the 1700s in Europe, institutions were developed to house, the mentally ill ('insane'). In turn, emergence of such facilities brought forth a societal conflict between what was the standard treatment regimen at the time and embracing moral treatment by the medical community (Hogan, 2001). By the 19th century, a connection was made between creative expression and psychological well-being (Stickley, Hui, Morgan, & Bertram, 2007). It was during this time that the artistic expression by a patient was introduced not as a by-product of psychoanalytic techniques but rather as a moral treatment regimen. The "unrestrained" use of imagination that patients were encouraged to explore in their art making began to be viewed both as curative and moral. Eventually, art sessions became less of a distraction technique and more of a tool to assist in the



acquisition of self-control for the patient. Additionally, there appeared to be an elevation of the patient's spirit as a result of art making and artistic expression.

"Art therapy" was first defined as a professional intervention in 1915 when Margaret Naumberg established the Walden School. Naumberg, an educator and a psychoanalyst, incorporated the use of art with psychotherapy for students at the school (Kastner & Burroughs, 1993). Art therapy continued to gain acceptance as an aspect of psychotherapy during the post World War II era in Britain (Heywood, 2003). One role of the psychotherapist is raising consciousness so the ego of the patient can benefit more fully from the creative experience. Champernowne, a Jungian analyst and psychotherapist, posited the focus for the art therapist should be with symbols and images created by the patient. Art therapy continues to be practiced by trained art therapists with patients having the express purpose of integrating the media of the visual artist with psychotherapy (Levick, 1999; Wadeson, 1980). In this way, the creative process allows individuals to become aware of and to help them to express their deepest emotions (Malchiodi, 1999).

Given that the experience of creating art has the potential to enhance self expression and insight into one's life experience, the distinction must be made between conducting art therapy and facilitating artistic expression with an individual. Similarly, the emphasis for both the creative art experience and art therapy is placed on the process for the individual not the product (Tate & Longo, 2002). Art therapy is commonly understood to mean the use of art and other visual media in a therapeutic or treatment setting (Dalley, 1984). Art therapy has been defined as the creation of art by a patient



with the express purpose of providing psychotherapy either by a trained art therapist or in conjunction with a psychiatrist. Indeed, art therapy has been able to effect a change for the patient as a result of the relationship that has developed between the art therapist and the individual. Based on the premise that the creative process is healing and life enhancing, art therapy has been employed by art therapists with patient populations other than those diagnosed with a mental illness.

Art therapy has been used as a strategy for crisis intervention in an acute care burn unit (Appleton, 1993). One 24-year-old burn victim was able to overcome the emotional and physical regression commonly experienced by burn victims in order to gain a new perspective on his life and plan of care. Favara-Scacco et al. (2001) found art therapy to be a useful coping strategy among children undergoing painful medical procedures. The researchers noted art therapy appeared to be helpful for the parents of the children as well. With greater self-awareness and an enhanced manner of support, these parents were able to interact more effectively with their children.

Through the integration of visual art with the principles of psychotherapy,

Callanan (1994) found that a group of frail and elderly patients were able to learn new

ways to express themselves as well as to interpret personal life situations. Art therapy, in

combination with music therapy, has been successfully used in controlling pain and

anxiety as well as enhancing communication with patients in a hospice setting (Trauger
Querry & Haghighi, 1999).

Nainis et al. (2006) sought to determine the efficacy of a one-hour art therapy session in reducing pain and emotional symptoms associated with cancer in adults



admitted to an inpatient oncology setting. The instruments used to measure the patients' symptoms and emotional states were the Edmonton Symptom Assessment Scale (EASS) and the Speilberger State-Trait Anxiety Inventory-State Scale (STAI-S). A total of 50 participants with a diagnosis of leukemia or lymphoma were enrolled in the study. A statistically significant reduction in eight of nine symptoms measured by the EASS was found. Additionally, a statistically significant decrease in state anxiety and increased feelings of calm, joy and pleasant experience were noted on most of the anxiety domains as measured by the STAI-S.

A myriad of treatment modalities that purport a better understanding of or improvement in the lives of women with breast cancer can be found in most professional journals and textbooks. Reports of clinical trials that seek to improve treatment outcomes for these women for can be found in many medical and nursing research journals. Be it assessing the benefit of listening to music while receiving chemotherapy (Bozcuk, et al., 2006), understanding the benefits of expressive writing for women with advanced breast cancer (Laccetti, 2007), or maintaining the sense of a valuable, unique and permanent self through art making (Collie, Bottorff, & Long, 2006), research findings reinforce the healing attributes of creative expression for women with breast cancer.

A 2006 study (Meraviglia) conducted by a nurse researcher sought to explore the effects of prayer and meaning in life in regard to spirituality within a group of women with breast cancer. The findings of the research suggested that encouraging women diagnosed with breast cancer to explore their spirituality was an effective method for dealing with the psychological and physical responses to cancer. A self-forgiving attitude



and spirituality were found to be indicative of fewer mood disturbances and better quality of life for a group of breast cancer survivors (Romero, et al., 2006). There exists a potential positive effect of creating art for the individual's sense of spirituality.

A study with women receiving chemotherapy for breast cancer was conducted to explore the meanings associated with the experience (Richer & Ezer, 2002). The findings of the nurse researchers suggested that there is an intrapersonal and interpersonal aspect of the chemotherapy experience for this population of women. These dimensions of receiving chemotherapy were further described from situational and existential perspectives.

Gabriel et al. (2001) tested the feasibility of art therapy as a supportive intervention with isolated adult patients who had undergone bone marrow transplant. A thematic analysis of the artwork created by these patients showed a strengthening of positive feelings, alleviation of distress, and clarification of existential and spiritual issues for the participants. The results of the study suggested that art therapy may be especially beneficial for patients who are dealing with emotional conflicts surrounding death in a safe setting.

Art therapy has been used with cancer patients after completion of chemotherapy treatment as well (Luzzatto & Gabriel, 2000). One group of patients met for a series of 10 weekly workshops which incorporated drawing, painting, visualization and collage. The goal of the program was to help patients to regain self-confidence and their self-identity in light of the cancer diagnosis and treatment. As a result, the researchers found three common responses to the questions, "What was helpful?" Three main themes were



elicited from responses of the 70 participants. A change in mood and feeling frequently described as joy, peace and freedom was found in addition to an increased self-awareness. This self-awareness was described positively by some patients while others became aware of an unpleasant side of themselves. Finally, the participants experienced a change in attitude toward others as result of the weekly sessions. Some of them said they became more trusting and had overcome fears of self-expression, other participants reported experiencing an increased compassion and respect for others as result of the group art experience.

McCaffrey (2007) conducted a study using three different interventions to determine the art therapy effects on older adults with mild to moderate depression. The first group walked thorough a garden for one hour once a week for six weeks. The second group walked through the garden with the same frequency with additional guided imagery provided throughout each walk. The third group participated in an art experience with an art therapist once a week for six weeks. The researcher viewed the third group as the control group. She was interested in learning whether the groups that walked through the garden would have the same response as did the group that participated in the art therapy. Data obtained by the researcher through focus group interviews at the end of six weeks found participants in all three groups thought the interventions were helpful in relieving depression and elevating mood.

Johnson and Sullivan-Marx (2006) reported on case studies obtained by conducting art therapy with two frail, elderly urban African American clients. Despite a variety of physical limitations experienced by each individual, study participants were



capable of using the art materials. The artwork created by each of the participants was bound into a booklet. For one participant, the book which was created with her drawings and paintings, served as a tangible evidence of her life and its worth. The book of the other woman included pictures of her mother and family members along with pictures cut from magazines, to honor the memory of her mother. When showing her book to others she related life stories that were symbolized by the pictures within the book.

More recently, Forzoni, Perez, Martigentti and Crispino (2010) conducted a study with patients while they were receiving chemotherapy treatment for cancer. The aim of the study was two-fold: to assess whether or not patients perceived art therapy to be helpful while receiving chemotherapy and to better understand in which way the art therapy was thought to be helpful. The researchers found that art therapy is useful in allaying some of the stress an individual experiences while receiving chemotherapy. The need fulfilled by the artistic experience varied among study participants. Improved mood and increased relaxation was experienced by some while others were able to express themselves through the art they created. This self-expression was construed as allowing the study participants to elaborate on their individual emotions.

While these studies were conducted by health professionals with specialized training in art therapy, the research laid important ground work for a better understanding of the potential benefit to the patient of facilitating the creation of art for purposes other than psychotherapy. A wide range of patient populations, which included those diagnosed with cancer, were the subjects of the research that served to identify the benefits of creative expression. The findings support the need for further description of the lived



experience of creating art for the population of interest in this dissertation - women with breast cancer.

#### Research Conducted by Those Other Than Art Therapists

The first art therapy initiative with cancer patients in a Scandinavian country was led by two occupational therapists (Ziesler, 1993). The focus of the group art activities was placed on the need of patients to express thoughts and feelings related to their illness or any other aspect of their lives through the art they created. An overarching goal of those group sessions was to maintain a safe and supportive environment where participants were free to express a multitude of feelings without fear of rejection or censorship.

Since that time an analysis by two psychologists of accounts from 35 women living with chronic illness provided insight into the meaning of art-making for the study participants (Reynolds & Prior, 2003). The researchers found the creation of art provided a means of regaining a positive self-image when the health of the individual was poor. Many of the women found the art-making offered a distraction from preoccupation with the illness and provided a meaningful activity within which to engage. The consensus of the study participants was that their art-making was viewed as an opportunity for personal growth. Additionally, some of the women developed new relationships with one another as a result of acquaintances made during the art-making sessions.

The same researchers conducted a study in follow-up to better understand the experiences that encourage some individuals to create visual artwork when living with



cancer (Reynolds & Prior, 2006). The results of the study suggest art-making as a leisure activity provided participants with the ability to maintain a positive personal and social identity. Some of the participants in the study reported the ability to resist labeling themselves by the cancer diagnosis as a result of continued art-making. Additionally, study participants described the relationships with one another as being founded on mutual interests as opposed to one based on illness. Among the motivations reported for continuing to create art for these individuals were proving oneself and sustaining an interest in this challenging activity.

The effect of creating art has been studied in individuals diagnosed with epilepsy (Anschel, Dolce, Schwartzman, & Fisher, 2005). The team of researchers, led by a neurologist, sought to identify a commonality in the quality of the sketched lines used in the drawings by patients with a history of seizure activity. The results of the study also revealed an 80% likelihood of patients diagnosed with a Non-Epileptic Event (NEE) seizure disorder to use 10 or more colors in the creation of their artwork compared to other study participants who used fewer colors in their artwork.

In a study commissioned by the Department for Culture, Media and Sport and the Department of Health in the United Kingdom (UK), a multidisciplinary team sought to provide evidence of the benefits of arts participation for a population with mental health needs (Secker, Spandler, Hacking, Kent, & Shenton, 2007). The activities included creating visual art, decorative design, ceramics, textiles and mosaic as well as performance art, writing, and photography. Sixty two participants provided the data analyzed in this outcomes study. Three standardized measures: empowerment, Clinical



Outcomes in Routine Evaluation (CORE) and social isolation were evaluated through the use of a questionnaire. Nearly all of the participants reported that engaging in the creative activities was helpful in increasing their motivation. In addition to increasing physical activity, they experienced increased hope, inspiration and meaning in their lives. While participating in the artistic experience, participants reported they were able to relax and focus on something specific. Finally, the study participants appreciated the supportive environment in which they were able to express themselves artistically. The ability to connect with others in this context decreased social isolation and increased self confidence of the participants.

In addition to the UK and the United States, creative art therapy has been widely employed for decades in Dutch mental health care as well (Visser & Hoog, 2008). The Cancer and Creative Art course was developed in Utrecht, the Netherlands in an effort to create an environment where cancer patients could develop coping skills through creativity and self-expression. Made up of eight weekly sessions, the participants participated in art therapy combined with relaxation, visualization and imagery exercises. The European Organization for Research and Treatment of Cancer (EORTC) questionnaire was used to evaluate overall quality of life and mood state was evaluated by the Profile of Mood State (POMS) as well as a questionnaire that evaluated the participants' viewpoint in regard to meaning of life. Each of the 35 study participants had been diagnosed with cancer. Most were female and the most common type of cancer was that of the breast. The results of the analysis of the data obtained prior to the sessions and afterwards suggest study participants were able to discover, express, and deal with their



feelings related to their cancer through their participation in the eight week course. The participants also reported experiencing personal growth and having supportive contact with other cancer survivors through the interactions that took place during the art sessions.

Teams of researchers comprised of a variety of disciplines have begun to investigate the effect of the creative art experience for diverse patient populations. Reported results indicate there is a decided benefit for creating art among the patient populations studied. Amid the findings are reports of an added benefit of enhanced interpersonal relationships among those who create art in a group setting with others who share a similar health challenge or diagnosis. The regaining of a positive self-image and experiencing an increase in self confidence as a result of participating in the creation of art has been reported as well. Creating art has provided a distraction from their illness for some participants while affording an opportunity for personal growth when being challenged through the creative art experience for others. Additionally, the creation of art in a group setting appears to provide an opportunity for members of the group to connect with one another and develop new relationships as a result of the creative art experiences.

#### Research Conducted of Women with Breast Cancer by Art Therapists

Borgmann, an art therapist, provided a rationale for using art therapy with women with breast cancer (2002). In three case studies of women with breast cancer, the researcher illustrated a woman's ability to identify coping strategies for a diagnosis of breast cancer through the self-expression experienced in art therapy. For one woman, the



ability to perform skills of self help was discovered through her experience with art therapy. A second woman was able to express herself more completely through art therapy which enhanced her ability to investigate her personal journey through breast cancer. The third woman found art therapy helpful in assisting her in dealing with the grief she was experiencing with the loss of her healthy self as a result of having breast cancer.

A multidisciplinary team of researchers in Sweden conducted a randomized controlled study of the effect of a 5 week art therapy intervention program on coping in women diagnosed with primary breast cancer (Oster, et al., 2006). The randomized study group (n = 20) received individual art therapy for 1 hour during postoperative radiotherapy each week while the control group (n = 21) did not. The study participants completed the Coping Resources Inventory (CRI) questionnaire on two occasions over the 6 month course of the study. The CRI is a tool used to identify resources available to an individual which are helpful for stress management. Significant differences were found between the intervention group and the control group in the social domain of the CRI used to measure coping resources at both points of measurement. The increased coping identified in the study group highlighted the need for support for women undergoing treatment for breast cancer. The findings suggest, further, art therapy may be one way to strengthen coping resources for these women.

Subsequently, the researchers employed a discursive approach in analyzing the field notes collected during interviews conducted with the study participants (Oster, Magnusson, Thyme, Lindh, & Astrom, 2007). A secondary analysis of the data found that



women in the intervention group discussed gender boundaries more frequently than did those in the control group. "Breast cancer as a challenge" and "stoicism in the face of adversity" were themes that emerged consistently in both groups of study participants. The themes of "confusion" and "conflict" were more common among the control group than among the intervention group.

A third randomized assigned study was conducted with the same population of women with breast cancer. The goal of this study was to measure the effect of the art therapy intervention on self-rated quality of life (QoL) for participants while receiving radio-therapy treatment (Svensk, et al., 2009). Women were randomly assigned to an intervention group with five art therapy sessions led by an art therapist once a week or to a control group that did not receive the art therapy. Two standard tools were used to measure quality of life for both groups: the World Health Organization Quality of Life (WHOQOL-BREF) and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-BR23 (EORTC QLQ-23-BR23). The WHOQOL-BREF is an abbreviated version of the WHOQOL-100 quality of life assessment tool. Overall, QoL and general health among the women who participated in the art intervention was positively affected when measured by the WHOQOL-BREF on the third occasion at 6 months. No significant differences in QoL between the control group and the intervention group could be measured using the EORTC QLQ-23. The findings of this study suggest the need for further qualitative inquiry into creating art for women with breast cancer in order identify and to better understand how the experience may enhance their quality of life.



Collie, Bottoroff and Long (2006) sought to gain an in-depth understanding of the differences in how women with breast cancer addressed psychosocial needs through the use of art therapy conducted by an art therapist compared with those who participated in art making without a therapist. Seven of the women had participated only in art therapy after their diagnosis of breast cancer, seven women had created art on their own and three of the women had done both. An analysis of the narrative data obtained from 17 study participants revealed four themes: (a) art and art therapy as a haven, (b) getting a clearer view, (c) clearing the way emotionally, and (d) enhancing and enlivening the self. The story lines were represented equally, with one exception, between the women who participated in art therapy and those who participated in art. Getting a clearer view appeared more frequently in the narratives of the art therapy group.

Participation in a creative arts therapy intervention was shown to enhance psychological well-being in women newly diagnosed with breast cancer (Puig, Lee, Goodwin, & Sherrard, 2006). This experimental pretest/posttest design study included 35 women diagnosed with Stage I and Stage II breast cancer. The women were randomly assigned to an experimental group that received individual creative arts therapy intervention or to a control group. The women in the experimental group received a total of 4 weekly creative arts therapy sessions. Tools used to assess for potential differences between the two groups were the Emotional Approach Coping Scale (EACS) used to assess emotional expression, the Expressions of Spirituality Inventory (ESI-R) measured spirituality and the Profile of Mood States (POMS) measured mood. Analysis of covariance (ANCOVA) was used to examine the effects of the individual creative arts



therapy. While the comparison of the EACS and the ESI-R between the experimental and control groups revealed a lack of statistical significance, the evaluation of psychological well-being between the two groups produced a clinically different result. Participants in the treatment group demonstrated significantly lower scores than those in the control group in tension-anxiety, depression-dejection, anger-hostility, and confusion-bewilderment after completing the creative art intervention.

The findings of recent research on the effect of creating art for women with breast cancer suggests there is a decided benefit for these women who engage in the creative art experience when conducted by an art therapist. The benefit of the creative art experience for this population when facilitated by one other than an art therapist remains unknown.

## Research in Creating Art Conducted by Nurses

Research conducted by Heiney, a nurse researcher, and Hope (an art therapist) sought to describe the structure and process of an art support group for adult patients with cancer (1999). Study participants met for six weekly one and a half hour sessions to create art that represented their personal perspectives on having cancer. Each session was comprised of studio time for creation of the art and discussion time. At the end of each session the participants completed a written evaluation tool. Major themes that emerged from the study participants open-ended responses were: (a) sense of decreased isolation, (b) a vehicle for expressing feelings, (c) gain of new perspectives, and (d) improvement of current and future coping. As a result the researchers found the creative process can be



utilized as a vehicle for self-discovery within the context of a supportive group environment.

Two nurse researchers, Deane and Fitch, teamed with Carman, an art therapist to conduct research to evaluate an art therapy program for adults with cancer (2000). Twenty one study participants, two of whom were male and 19 were female attended one or more of the three art programs. The program consisted of 16 weekly two-hour sessions. Each encounter had both a gallery component and a studio portion. The participants were given an opportunity to learn about art history and the technical aspects of creating art in the gallery segment while the studio component gave them the opportunity to create their own art. The study participants provided the program evaluation through comments elicited by the researchers. As a result of participating in the art program the participants experienced a decrease in cancer related physical symptoms along with a reduction in "tiredness". Study participants also reported that the art intervention distracted them and focused their attention on something positive. They judged the intervention to be a pleasant experience that was relaxing, calming, productive, and worthwhile. Still others viewed their art work as "cathartic." The activity allowed them to explore their emotions through drawing in spite of a range of artistic abilities and levels of expertise. Participants found "joy and safety" in dealing with their cancer diagnosis within the boundary of the art group. The researchers found the art program demonstrated value for patients to explore their feelings related to cancer.

A pretest/posttest, quasi-experimental design study was conducted by three nurse researchers to test the efficacy of a creative arts intervention with family caregivers



(Walsh, Martin, & Schmidt, 2004). This research is among the first studies conducted by nurse researchers into the effect of the creative art experience for a patient-related population. This 6 month study was implemented at the bedside with 40 family caregivers of hospitalized cancer patients. The creative arts intervention included 5 choices for creating art. Participants were able to choose to make a poster using Polaroid pictures, an abstract design with watercolor, draw a mandala, create a silk wall hanging or a silk rubbing. Standardized tests used to evaluate the pretest and one hour posttest effect of the intervention were the Mini Profile of Mood States (Mini-POMS), the Beck Anxiety Inventory (BAI) and the Derogatis Affects Balance Scale (DABS). A pairedsamples t test was done to evaluate if the art intervention would reduce stress, decease feelings of anxiety and promote positive emotions. A significant decrease in stress in the participants was noted between the pre-intervention and post-intervention scores. Likewise, there was a significant decrease in the pre-intervention and post-intervention anxiety scores. The participants exhibited a statistically significant increase in positive emotions as assessed by the DABS pre-intervention and post-intervention. In addition to what is known about the effect of art on healing, the results of this study suggest involvement with art can be beneficial for family members and other caregivers of patients with cancer as well.

The hermeneutic, phenomenological method was used by one nurse researcher to interpret the lived experience of art and healing for 63 study participants (Lane, 2005b). Those participating in the study were hospitalized patients (n=23), artists (n=18), family members of patients (n=12) and healthcare providers (n=10). Study participants created



art through painting, sculpting, dance, as well as journal and poetry writing. Data obtained from interviews conducted with those enrolled in the study spanned a 4 year period and was analyzed by the nurse researcher using van Manen's method. Lane found participants often experienced a shift of consciousness as part of the creative art experience. In addition, the experience of art and healing emerged as a spiritual dimension. Lane refers to this as "spirit body healing" and identifies the concept as an important aspect of participation in the creative art experience.

Another study involved patients who attended an arts workshop conducted by nurses specializing in mental health (Stickley, Morgan, & Bertram, 2007). The workshop included visual arts, writing, poetry, music and lyrics. Study participants (n=11) were interviewed by the researchers after participating in the arts activities. The interviews served as the data that were analyzed. Narrative discourse analysis was employed to elicit common themes uncovered in the analysis of the participants' dialogue. Among them were the idea the art was reflective of the emotions of the study participants; and, art making provided a sense of achievement as well as being inspirational and motivational. Additionally, the artistic experience provided an opportunity for socialization for the participants while allowing each of them to maintain individuality and hope. Freedom, identity, and self-expression were common themes throughout the discourse of the study participants.



# Research Conducted by Nurses of Women with Breast Cancer

To date only two studies conducted by nurse researchers have sought to describe women's experience with breast cancer through art. Ponto (2003) organized an art exhibit to display women's stories of breast cancer in an effort to increase cancer awareness and also to provide support for the women. The artists used photography, paint, ceramics, sculpture, video textiles, and tapestry to tell the stories of 100 breast cancer survivors.

Predeger (1996) explored the meaning of healing through expressive arts with 18 women living with breast cancer. Photography, watercolor, collage, poetry, and a common desire among the participants to combine words with images were the source for the data in the study. The participants' reflections on the art, conversations among the study participants, the researcher's field notes and audiotaped focus group sessions underwent thematic analysis by the nurse researcher. The theme "losing control, gaining control" was common to the women in this study. Art making was described as an important way of gaining control as well as providing a pathway to healing for these women. A desire was identified within the group to move beyond the individual and to reach out to help others. The group sessions were an environment in which the women felt safe and thus were comfortable expressing their needs to each other. Gain of control that had been lost as a result of having had breast cancer emerged as a predominate theme in this study.



# **Summary**

From the earliest recordings of medicine to the present, breast cancer continues to afflict women at a rate that has been unchanged over time. While conventional therapies focus on healing and recovery for women from breast cancer, findings suggest there is a need for treatment options beyond those of medical interventions. The creation of art that is healing and can be the source of other types of relief has steadily gained attention.

Initially conducted as a form of psycho-therapy for those who suffered with mental illness, the creation of art for the sake of the healing effect is no longer conducted exclusively by art therapists. Nurses, physicians, and therapists from a variety of different disciplines have been exploring the benefits of creating art for their patients. Among the range of populations and diagnoses for which these benefits can be explored is that of women with breast cancer.



# CHAPTER 3 METHODS

### Introduction

This chapter describes the qualitative research approach of phenomenology used to answer the research question: What is the lived experience of women with breast cancer who create art? The sample size, methods used for recruitment, data collection and analysis of the data for this study are discussed.

# Phenomenology: A Description of the Lived Experience

The evolution of nursing science has depended on theories and conceptual models that were borrowed from other disciplines (Phillips, 2004). The medical paradigm, which fosters a disease-oriented reductionist approach having a focus on underlying defects or abnormality of function, has been used most often. Research that endeavors to quantify data and reject or accept a hypothesis has an important role to play in advancing nursing science; however, this type of inquiry cannot answer every research question. Essentially, a quantitative reductionist approach tends to view the study of human beings from a third-person observational perspective. Alternatively, for nurse researchers there exists an interest in the human response to actual and potential health problems. Expanding this area of inquiry can offer insights about the 'lived experience' of individuals within the context of their reality and is captured through the use of qualitative research methods.

The research strategy used in a qualitative study is determined by the purpose of the study and the nature of the question to be answered (Morse, 1994). Phenomenology



was the method used in this dissertation to provide the researcher with a relatively unbiased and objective account of the phenomenon (Gallagher & Zahavi, 2008; Giorgi, 1989). The focus of the phenomenological inquiry was the description of the human experience of creating art by women with breast cancer. Given that the understanding of an individual's everyday world is the foundation of scientific explanation, a means for describing that lived experience was the focus of this dissertation. Identification of commonalities among women with breast cancer who created art provided enhanced understanding of their lived experience.

## Rationale

Traditional science is not focused on measuring the lived experience of individuals because of the inherent limitations of quantitative measurement and appraisal through the senses (Le Vasseur, 2003). Sofaer (2002) posited that the development of knowledge involves the gradual elimination of uncertainty. In the process of diminishing the unknown by obtaining answers, there remains an element of uncertainty in regard to whether or not the right questions have been asked. As answers are acquired for the questions that are put forth, there remains an additional uncertainty about whether or not all of the questions have been asked. The phenomenological method of inquiry allows for the suspension of the natural attitude while providing for a deeper description of the experience of creating art while coping with breast cancer. Therefore, rather than focusing on the questions that are asked of the study participants, the focal point is on the



process of bracketing presuppositions and allowing the participants' description of the lived experience become apparent.

The phenomenological method was used to answer the research question: What is the lived experience of women with breast cancer who create art? The phenomenological approach is exploratory in nature and, as such seeks to describe a particular phenomenon from those with first hand experience with the phenomenon. The description of the experience should be as free from unexamined presuppositions on the part of the researcher as is possible (Spiegelberg, 1975).

Phenomenology has its roots in the philosophical perspectives of Edmund Husserl (1859-1938), a German mathematician and philosopher (Spiegelberg, 1994). A guiding theme of Husserl's philosophy and, ultimately an underlying assumption of phenomenology, is that of "going back to the things themselves" (Husserl, 1900).

According to Husserl (1900), phenomenology involves the examination of consciousness, or the way one experiences the world (Husserl, 1952; Polkinghorne, 1989a). For Husserl, an individual's experience is the fundamental source of meaning and knowledge (Racher & Robinson, 2002). Data gathered through phenomenological inquiry are more than an individual's recounting of the subjective experience, however. Rather, the description of the lived experience, according to Spiegelberg (1994) provides an avenue for discovery of the essential structures of that experience. Husserl believed that phenomenology should return to the essences that constitute the perceptual consciousness of the human world. Consciousness is more than a mere feature; it is the way of being that occurs with the experience (Zahavi, 2003).



The concept of intentionality is a key component of consciousness (Giorgi, 1997; Spiegelberg, 1994) that is, every act of consciousness is directed toward an object or essence that transcends the act itself. In the study of human consciousness there are features of a particular lived experience that are common to others who share the experience. These common features are referred to as essences or eidetic structures which are universal to the extent that they can be found in everyone's experience of that sort. When commonalities are identified general characteristics of a particular phenomenon can be described (Lopez & Willis, 2004).

The goal for the researcher in this study was to attain a transcendental approach (Spiegelberg, 1994) which suspended all assertions about reality other than those evidenced in the lived experience of each study participant. Specific techniques used to ensure rigor in adopting this transcendental approach or attitude are discussed later in this chapter.

#### Methodological Assumptions

Giorgi (1997) claims the analysis of the data from which the knowledge is derived must involve a systematic process. Giorgi provides specific steps for phenomenological studies (A. Giorgi, personal communication, April 29, 2009). Sometimes referred to as the Duquesne Phenomenological Research Method, this systematic approach for analyzing phenomenological data was pioneered by Giorgi during his tenure as a researcher at Duquesne University in Pittsburg, PA. (Giorgi, 2008). Table 1 contains an



overview of Giorgi's method consisting of seven steps. This systematic approach to analyzing qualitative data provides the framework for this study.

Table 1 Giorgi's Process for the Analysis of Phenomenological Data

Steps	Descriptors		
Step 1	Guided by phenomenological principles		
Step 2	Selection of participants with a diagnosis of breast cancer who possess the lived experience and who have a natural attitude perspective on creating art		
Step 3	An attitude of phenomenological reduction is taken by the researcher		
Step 4	The transcribed data (descriptions of the lived experience) are read in their entirety in order for the researcher to obtain a sense of the whole		
Step 5	The researcher re-reads the description so that the data can be broken into meaning units		
Step 6	Through imaginative variation, the researcher transforms the participant's natural attitude into expressions that more adequately convey meaningful insights		
Step 7	The transformed meaning units are used as basis for writing a typical structure of the lived experience of creating art for women with breast cancer		

# Integration of Phenomenological Principles

Giorgi's (2008) method of analysis, coupled with the assumptions of phenomenology as outlined by Cohen (1987) guided the development and data analysis processes for this dissertation. Underlying principles of phenomenology include the notion that human existence is of interest and has meaning, in that one is a being in the world. An individual's existence is not as one thinks it should be but, rather, what it is, as it is lived. The world of the individual is understood in terms of the lived experience of that person and as such is critical to phenomenology. In this dissertation, each woman's



description of creating art while living with breast cancer offers a description of her unique lived experience. Understanding of these descriptions occurs within the context of the world belonging to, that is, as it is experienced by each woman.

## **Epoché**

In keeping with the methodological principles of phenomenology, the study was started with a suspension of the natural attitude of the researcher in her interactions with the study participants. A critical first step for the researcher was to put aside pre-existing theories and personal biases, for example any preconceived notions of how beneficial creating art might be for patients. Epoché, a term adopted by Husserl, refers to this setting aside of theories and biases in order to gain the pure description of a phenomenon that is made possible without being colored by prejudice or preconceived ideas (Cohen, 1987). Gallagher and Zahavi (2008) suggest that epoché is an exclusion of the belief in reality, or in theories about reality, in an effort to describe a phenomenon. Accordingly, epoché is the suspension of beliefs, the neutralizing of our everyday natural attitude toward reality. This, thereby, allows the researcher to focus more sharply on her own experience or the experiences of the study participant.

Recalling his mathematical background, Husserl introduced the practice of "bracketing" as an analogy for the action of the suspension of beliefs (Drew, 1999). In aiming for a pure description of the phenomenon of interest, this researcher sets aside her preconceived assumptions about the phenomenon of interest by identifying and examining past knowledge about the phenomenon through bracketing. In this study



bracketing is accomplished by reflecting on these biases and then writing about them in a journal, thereby becoming aware of them. A review of the journal entries as the study progressed revealed three common assumptions held by the researcher in regard to the phenomenon of interest.

- 1. Creating art is a distraction. While concentrating on the creation of a piece of artwork the artist is necessarily focused on the materials and techniques needed to create the art. Whether considering a color choice or the placement of a line or brush stroke, the artist is likely to be thinking only about the task at hand. There is potential for the artist to be transported away from many or all of the aspects of day to day life while creating art.
- 2. Creating art is a method of self-expression. When looking at art created in any medium the observer may be drawn to wonder what idea or message the artist was conveying through the piece of art that was created. Perhaps the act of creating the art is the expression of the thought or emotion and the final product serves as a visual reminder of what the artist was experiencing at the time of creation. Possibly the artwork conveys a thought, idea or emotion that the creator was unable to express any other way. When considering the possibility that the creation of art provides a mode of expression for the individual creating the art, what, then is the effect for the artist?
- 3. Creating art is healing. An extensive review of the literature was purposely delayed until after the data were obtained from study participants in order for the researcher to remain unbiased as much as possible. The researcher's knowledge of the healing benefit of creating art that was gained through doctoral course work, communication with researchers in the field of art and healing as well as individuals who



have firsthand experience was a constant reminder that, for many, the creation of art has a healing effect.

These biases were bracketed, essentially put aside, for the purposes of conducting this study. Rather than providing a hypothesis to be supported or to be found null, these assumptions supplied direction for the researcher to remain presuppositionless. In this way, there was a suspension of the natural attitude and epoché was achieved.

### **Eidetic Variation**

Spiegelberg (1994) cited two stages of phenomenological method: "eidetic reduction" and "phenomenological reduction." Eidetic reduction is a rendering of facts that are specific to the individual and reducing these to general essences that are more universal to the phenomenon. All reference to the individual or particular is removed through eidetic reduction. Husserl (1952) referred to this process as free variation, wherein an individual imagines an instance of the phenomenon under consideration; and, then examines the range of possible forms the phenomenon can take. By adding and eliminating features, and noting at what point the original phenomenon is no longer recognizable, the essences or essential aspects of the phenomenon can be identified. The purpose of this exercise is to make concepts fully lucid and unambiguous (Paley, 1997).

The process of eidetic reduction and phenomenological reduction gave rise to many forms of the phenomenon in the course of gathering and analyzing the data for this dissertation. The researcher sought to skillfully elicit the necessary information from each study participant in such a way that the general essences would be rendered from the



interview data. Most challenging was the identification of the variety, in shape and context, of the phenomenon that were presented by the study participants.

## Protection of Human Subjects

Application for authorization of this dissertation was obtained from the University of Central Florida (UCF) Institutional Review Board (IRB) (Appendix A). Upon approval for this dissertation from the IRB, study participants were contacted by the researcher via telephone or in person. Women who met the inclusion criteria and expressed an interest in participating in the study were mailed the informational cover letter (Appendix B), two copies of the informed consent form (Appendix C), and the consent to photograph form (Appendix D). These four documents were mailed to each potential study participant along with a self-addressed, stamped return envelope. A participant was instructed to read the letter and the informed consent form. If she agreed to participate, each woman was asked to sign one of the forms and return the document to the researcher in the envelope provided.

Upon receiving the signed document, the researcher contacted the women by telephone to provide complete details about the study and answer questions. In this conversation, the study participants and the researcher determined a mutually convenient time, date and location for an in-depth, face-to-face, interview.

To protect anonymity and assure confidentiality, prior to the interview each participant was assigned a unique identifying number, composed of the date the interview (MMDDYY) followed by the participant's initials. A single master list that identified the



study participants with their unique identifying numbers along with the signed informed consent forms were stored in a locked cabinet in the home of the researcher. This secured cabinet was also used to store transcriptions of the interviews, corresponding field notes and, photographs of the study participants' art work. The researcher had the only key to the cabinet.

Transcripts of the recorded interviews were created in MS Word™ by the researcher. The electronic data were stored in a password protected computer, on a separate USB drive as well as backed up on the researcher's personal external hard drive. Consent forms, digital voice recordings, transcriptions and field notes will be retained for three years, at which time all materials can be destroyed, per the requirements of UCF's IRB (B. Ward, personal communication, April 16, 2008).

#### Recruitment, Selection and Protection of Participants

The selection of participants was restricted to those women who possessed the lived experience and who had a perspective of the natural attitude of creating art with a diagnosis of breast cancer. Purposive sampling was used to recruit volunteer study participants who were able to contribute to the description of the phenomenon of interest under study. Volunteers who were considered for participation were females at least 18 years of age who were; (a) English speaking, (b) had been diagnosed with breast cancer and (c) had begun to draw, sketch or paint after receiving the diagnosis of breast cancer.

The decision was made to recruit women who began to paint, sketch or draw *after* receiving the diagnosis of breast cancer. The rationale for choosing these inclusion



criteria was that the lived experience for a woman who painted, sketched or drew before receiving the diagnosis of breast cancer may differ from that of a woman who began to create art after the experience with breast cancer. In keeping with the purpose of phenomenological research, which is to describe the structure and essences of an experience, the researcher sought a sufficient number of descriptions of the variations of the lived experience of creating art.

Due to the lengthy interviews in which the data are collected and the labor involved in differentiating meanings from within that data, Giorgi (2008) recommends the enrollment of at least three study participants. Four participants met the inclusion criteria for the highly focused phenomenon of interest in this dissertation.

Recruitment of potential participants for this study was through word of mouth on the part of the researcher with artist communities in Orange, Sarasota and Manatee counties in Florida. Referrals were also sought from two well-known Florida artists and from members in the Oncology Nursing Society chapters in Orlando and Tampa, Florida. Written recruitment materials were displayed in art supply stores and settings where art classes were taught in Orlando and Sarasota, Florida as well as in two radiology centers located in Orlando and another in Pembroke Pines, Florida.

Initial contact with a-fore mentioned referral sources was made by the researcher to outline the purpose and expectations of participation in the study. Upon agreeing to participate in the recruitment efforts, a flyer (Appendix E) describing the study and the participant inclusion criteria were disseminated to the referral sources. Printed in color on glossy paper, the flyer was aesthetically pleasing and sought to capture the attention and



interest of prospective study participants. In turn, referral sources were asked to distribute a flyer to individuals or patients who fit the inclusion criteria. Weekly telephone contact was maintained with the referral sources by the researcher as a way to remind them about the study and to answer any questions that may have arisen.

The researcher subsequently was provided feedback from referral sources that a trifold brochure (as opposed to posting the one-page flyer) might be a more visible and effective marketing tool to recruit prospective study participants. Additionally, a flyer that was posted on a wall or bulletin board tends to be removed by an interested individual; hence, the potential for a missed recruitment opportunities. Based on that feedback, a tri-fold recruitment brochure (Appendix F) was developed by the researcher; submitted to and approved by the UCF IRB; then, placed in a visible public site by the referral sources.

Surprisingly, on the first day the researcher was contacted by a woman who had begun to create art through photography after her diagnosis of breast cancer. However, that trend did not persist; and, after three months of concentrated recruitment efforts only one participant had been enrolled in the study. While the researcher was contacted by five additional prospective study participants, these women did not meet inclusion criteria. Three of the women had created art by painting prior to their respective breast cancer diagnoses; one woman had begun to create doll clothes; another began creating embroidery after a diagnosis of breast cancer.

At this juncture the researcher sought advice from the dissertation advisory committee on revising the inclusion criteria. In an effort to eliminate any confounding



elements in describing the lived experience, an initial decision was made to exclude women who had created art prior to a diagnosis of breast cancer as opposed to including participants who created art prior to the diagnosis. Clearly, the response to recruitment efforts raised the question as to whether the inclusion criteria could be modified to include any woman with breast cancer who created art by painting, sketching or drawing be it before or after receiving this diagnosis. The dissertation committee members were unanimous in their recommendation to make this change in the inclusion criteria. An addendum to the participant inclusion criteria was requested and granted from the IRB to reflect this modification in the study.

## **Data Collection Procedures**

Data for this dissertation were obtained from individual, in-depth interviews conducted by the researcher with each study participant. The goal of each interview was to obtain a rich description of the participant's subjective experience with creating art. The length of time to conduct each interview varied with each study participant. An emphasis was placed on guarding against leading the participant's responses with questions that compelled her to respond in a certain way. Equally important was the development of questions that guided the interview without steering the dialogue in one particular direction.

The researcher recorded all of the interviews using the Sony Voice Plus All-In-One Digital Voice Recorder ICD-U70<sup>TM</sup>. That particular device eliminated the inherent challenges of using a traditional tape recorder, e.g., disruption of changing tapes with



potential loss of data. The researcher made field notes during each interview which were used to augment the data being recorded. Once transcribed, the data were printed. Data were formatted in three-inch left justified columns, and the documents were placed in successive order along the left border of an 11 x 14-inch sketch book.

### Interviews

Using a guide designed by the researcher, the interview included six components:

(a) warm-up, (b) interview, (c) reflection, (d) clarification, (e) request for examples, (f) refocusing after a digression as needed, and (g) photographing each participant's artwork. Appendix G contains the interview guide. The researcher's goal was to explore and describe the essence of the life experience, grounded in a participant's natural context, that is to say their 'Lebenswelt' (Spiegelberg, 1994). Lebenswelt, is Husserl's (1900) German term. When translated into English the word means 'lifeworld'. This refers to the experienced world of one's everyday life. The overarching goal of the researcher was to elicit a rich description of the lebenswelt of each woman.

An initial interview with each study participant was based on the availability and convenience of the participant. Half of the study participants chose to have their interviews conducted in their homes where they created their art. The other half chose to have an interview conducted at their place of employment which also contained pieces of their artwork. Both of these women brought additional examples of their artwork in to the workplace for the researcher to view and photograph.



While conducting an interview the researcher conveyed an attitude of interest, safety, trust and acceptance (Jasper, 1994). The interview began with a warm-up question in an effort to establish rapport between the researcher and the study participant. The participant's description of an experience other than the phenomenon of interest was used to stimulate rich dialog in detail that would lead into discussion about the phenomenon of interest. As the vivid and detail-filled conversation proceeded, the participant eventually was asked to describe her experiences with creating art after a diagnosis of breast cancer. Since each of the study participants was a painter, the lead in question was, "How did you come to know you wanted to paint after your diagnosis of breast cancer?" The interviews were purposely iterative and nonlinear which allowed for a full description of each woman's lived experience.

Several interview techniques were utilized to ensure that the data were clear, comprehensible, and as accurate as possible. The researcher used reiteration, wherein the researcher occasionally found it necessary to restate or rephrase a statement made by the study participant in order to obtain a deeper description or understanding of the phenomenon of interest. On occasion, the study participant was asked to clarify a statement or describe a particular subjective experience further. The researcher frequently requested examples and enhanced details in order to deepen the description of the lived experience from each participant. In the event that a study participant digressed from the purpose of the interview, the researcher reformulated what the study participant had said up to the point that the conversation wandered in order to get the participant back on



topic (Petitmengin, 2006). This strategy presented an opportunity for the researcher to check the restated interview for accuracy with the study participant.

The interviews ranged from 35 minutes to two hours in length. While there was only one scheduled interview with a participant, each woman was invited to contact the researcher if she wished to provide additional information after the initial interview.

None of the participants initiated follow up contact with the researcher. A second interview was conducted with three of the four study participants. In most cases, the data obtained in the follow up phone contact yielded additional information that added to what had already been described about the phenomenon.

Photography was an additional data source for the study. Photographing the study participants' art work provided an opportunity for the researcher to obtain additional perspective of participants' artistic expression. Photography has been used to enhance qualitative nursing research and to enhance data collection strategies (Hagedorn, 1994). Additionally, according to Wertz (2005), the findings of phenomenological research can be presented and summarized through the use of photographs. Each study participant was asked for permission to have some of their art work photographed by the researcher. All of the study participants agreed without hesitation.

## **Enhancing Data Quality**

Whittemore et al. (2001) indicated that while rigor is essential to any research endeavor; it is unclear what criteria will reflect the assumptions of credibility within various types of qualitative research. Maxwell (1996) referred to credibility, as the



accurate interpretation of the data, and authenticity as descriptive and interpretive validity. Polkinghorne (1989) posited that the validity of phenomenological research could be substantiated by the persuasiveness of the phenomenologist's presentation of the findings. Accordingly, there were two notions that served as guides for the quality of this dissertation: (a) that the transformation of the raw data into phenomenologically-informed expressions can be traced back to the meaning units that were developed from the data, and (b) that the synthesis of the transformed meaning units into a general structural description of the phenomenon holds meaning for the study participants.

Lincoln and Guba (1985) used the term "trustworthiness" in evaluating the overall rigor of qualitative research. They identified four types of trustworthiness: (a) credibility of the findings as viewed through the eyes of the study participants: (b) transferability or the extent to which the findings can be transferred to another similar setting or situation: (c) dependability, reflecting the idea that the research would produce similar or consistent findings if carried out with similar study participants at another time, and (d) confirmability which charges the researcher to provide evidence that corroborates the findings.

Credibility and confirmability can be achieved through respondent validation (Mays & Pope, 2000) or member checking (Sandelowski, 1993). Member checking is the practice of reviewing the researcher's analysis of the data with one or more study participants for the purpose of verifying the accuracy of the interpretation (Sandelowski, 1998). This is an approach that is congruent with ensuring interpretive validity of the study findings.



For this study, member checking was achieved by sharing themes that were elicited from the last three interviews with the first interviewee. The observations of the first study participant provided intersubjective verification in validating the researcher's findings and were incorporated into the analysis of the data. Transferability and dependability were exhibited in the consistent and comprehensible accounting of the data collection, as well as the use of Giorgi's systematic approach to the data analysis.

## Reflexivity

In contrast to quantitative research methods which seek to suppress researcher subjectivity, it is crucial that the qualitative researcher become aware of how the researcher's personal philosophies have developed and the ways in which those belief systems underpin the study. Within qualitative research, reflexivity assists the researcher in identifying the impact of the researcher on the study design, data collection, analysis of the data, and presentation of the findings (Gough, 2003). The phenomenological data resulting from the study is the combined product of the study participant, the researcher and their relationship (Finlay, 2002). Bracketing, as described previously, provided reflexivity for the researcher in the ongoing exploration of the mutual meanings of that emerging relationship while yielding both interpretation and insight (Drew, 1999).

## **Journaling**

Reflective journaling was done by the researcher on a daily basis. For this study, journaling aided the researcher in identifying presuppositions and biases as well as helped



to clarify the parameters of the interviews (Polkinghorne, 1989a). Filling a journal page with ideas, reflections and free-formed thoughts almost every day was essential to separating the researcher's lived experience from that of the study participants (M. Rockwood-Lane, PhD, RN. personal communication, April 13, 2007). Journaling also enabled the researcher to maintain an on-going log of the researcher's insights, questions and concerns (Lamb & Huttlinger, 1989).

As the verbal and non-verbal interaction between the researcher and participant takes place, there is a potential for confusion to develop between each of their subjectivities. There is a possibility that an ambiguity may develop that renders the researcher unable to identify where the researcher's reality ends and that of the study participant's begins. Wall et al. (2004) recommended the use of journaling in a 'reflective diary' by the researcher as an important part of preparing to conduct interviews with study participants. In their study of the lived experience of patients diagnosed with Non-Hodgkin's Lymphoma, the researchers found journaling before conducting each interview presented an opportunity to identify and set aside issues specific to the research. Utilized as a 'pre' action, the researchers were able to bracket presuppositions about the research through journaling. The authors referred to the journal entries recorded immediately after conducting an interview as bracketing 'in' action. Journal entries made during this time provided an opportunity for the researchers to reflect on circumstances and unplanned events that occurred during the interview. This contemplation can be helpful in gaining insight into potential interference with describing the phenomenon of interest in subsequent interviews.



For the sake of precision in this study, the researcher attempted to engage in at least one introspective activity each day during the data gathering and analysis portions of this dissertation. While providing an opportunity for self-reflection, journaling served as a means for the researcher to bracket any preconceived ideas or beliefs she may have had about the lived experience of creating art for the study participants. Bracketing 'in' action provided an opportunity for the researcher to embrace knowledge gained and to incorporate that new information as a guide for subsequent interviews.

## Data Management and Analysis

Analysis and coding of the data was done concurrently while subsequent interviews were conducted. Questions were asked in subsequent interviews based on information obtained in previous interviews as well as on the researcher's emerging insight about the lived experience of creating art. Concurrent analysis processes enabled the researcher to validate emerging themes. As repeating and enduring patterns emerged in the analysis, the focus was on bracketing that knowledge in the researcher's reflective journaling.

Data were collected through a total of seven face-to-face interviews conducted with the study participants by the researcher. Two interviews were conducted with three of the participants and one was conducted with the fourth. The development of the interview guide was directed by the researcher's interviewing experience, literature on conducting interviews in qualitative research as well as input from members of the dissertation committee. The interview guide was used to generate broad and open ended



questions in an effort to ensure all topic areas were addressed in the open-ended interviews conducted with the study participants.

Each recorded interview, the transcriptions of the interviews, field notes made by the researcher during the interview, as well as any photographs taken of study participants' artwork, provided a data set for each study participant. Each data set was labeled with the study participant's unique identifying number.

A single researcher coding the entire data set ensures the highest possibility of coding consistency across the interviews (Polit & Beck, 2004). Conversely, the potential also exists for a single researcher to unwittingly interpret the data from a preconceived perspective in spite of the steps taken to remain reflexive through out the study. A second nurse researcher, familiar with qualitative research, was enlisted to read the transcriptions of the interviews. Rather than providing inter-rater reliability for the purpose of ensuring different observers make the same interpretation from a positivist perspective (Searle, 1999), this step was taken to ensure reflexivity on the part of the researcher.

### Phenomenological Reduction

A key feature of phenomenological inquiry, in the tradition of Husserl, calls for a transcendental attitude on the part of the researcher (Lopez & Willis, 2004).

Phenomenological reduction involves the identification of a starting point for the inquiry that escapes the assumptions that characterize the commonplace world and natural attitudes. In methodological terms, having a transcendental attitude requires constant assessment of the researcher's impact on the inquiry. In keeping with the philosophy of



Husserl's phenomenology, one of the steps of this study was bracketing the natural attitude of the researcher and her views through phenomenological reduction (Cohen, 1987). As phenomenological reflection is directed toward the experience itself and as objective considerations about reality are set aside, an optimal focus on the participant's description of the essential lived experience became possible (Paley, 1997).

The goal of phenomenological reduction is that of freeing the analysis from extraexperiential presuppositions (Giorgi, 2008). Through a process of rigorous reflection (which included journal keeping), the researcher was able to attend to the experience itself without the interference of preconceived notions or theories that may have occluded the original awareness of the phenomenon of interest (Munhall & Chenail, 2008).

In this study, the reduction called for the phenomenological researcher to bracket past knowledge, theories and her own expectations about the creation of art by women with breast cancer so that the researcher could be fully present to the experience as described by each study participant (Giorgi, 1997; Morse & Richards, 2002). This "presuppositionlessness" approach allowed the researcher to identify, with certainty, judgments about the reality of the phenomenon without external influence (Ray, 1994). This process eventually led to the description of the essential or invariant characteristics of the phenomenon that were common among all the participants.



## Intersubjective Corroboration

The description and essential structures of the phenomenon of interest are not merely connected to the individual or unique circumstance but, rather, should be compared to the lived experiences of others (Gallagher & Zahavi, 2008). An opportunity exists for discovering whether or not the essential structures of creating art for women with breast cancer are shared by others across different contexts. This may, in turn, determine the transferability of the research findings beyond the immediate study. A comparison of the descriptions of the phenomenon under study with the results of similar research provides an opportunity for ascertaining the universality of the phenomenon.

Intersubjective verification was carried out within this study in two ways. As suggested by Gallagher and Zahavi (2008), phenomenological descriptions can and should be compared with descriptions of others. The findings of Predeger (1996) and Ponto (2003) describing the lived experience of creating art for women with breast cancer were compared to the emerging essential structures of the phenomenon described in this study. Because the researcher was aware of the findings of the two previous studies, she made a concentrated effort to bracket those results through journaling in order to maintain reflexivity in the course of conducting interviews and analyzing the data. After analyzing the data, however, a comparison was made with the findings of the other studies. The intersubjective corroboration between these three studies is presented in the findings of this dissertation.

The second way intersubjective verification was accomplished was by taking the description of the essential structures of the phenomenon back to the study participants



for their review through member checking. Of the four study participants, only Anna and Beth were available to review the essential structures of the phenomenon as presented by the researcher. Both women were in agreement with the description of the phenomenon presented by the researcher.

### Initial Reading of Each Transcript

Prior to transcribing the interview, the researcher listened to each recorded interview while reviewing any field notes that may have been taken during the interview. The researcher retained pauses, nonlexicals such as "uhm" and "unh," false starts and emphases in the document in an effort to record the study participant's narrative as authentically as possible (Riessman, 1993). This procedure helped the researcher to grasp the participant's expression and intended meaning as well as to attain an overall sense of how the parts of each of the interviews were composed. In keeping with the holistic approach of phenomenology, each transcribed interview was first read and viewed in its entirety by the researcher (Giorgi, 2008). Additionally, the researcher carried out reflexive journaling prior to reading each of the transcribed interviews.

# **Identifying Meaning Units**

For this study, the researcher created an MS Word<sup>TM</sup> document with extensive margins alongside the numbered lines of each transcribed interview. The pages of the documents were stapled to the left edge of the sheets of an 11 inch by 14 inch drawing tablet. The data were managed by breaking the transcriptions into parts (Giorgi, 2008).



While reading the transcript, the researcher placed a slash mark after each transition in meaning within the study participant's dialog. This transition in meaning from one idea to another constituted the parts of the data and were termed meaning units.

The meaning units were further grouped in blocks of text by highlighting them with different colors. The grouped portions of the narrative described various aspects of the lived experience of creating art for the study participants. While taking care to use the same words, the researcher then rewrote these blocks of text in a column to the right of the printed text (N. France, PhD, RN, personal communication, February 21, 2008).

Visual "horizontalization" of the data presented each statement as having equal worth and served to develop a list of non-repeating, non-overlapping statements (Creswell, 1998).

Essentially, the process of phenomenological inquiry is furthered during the reflection that takes place on the part of the researcher through the reading and rewriting of the data (Morse, 1992).

### Imaginative Variation Conveys Data into Scientific Meaning

The natural attitude expressed in the words spoken by each study participant was transformed through imaginative variation by the researcher. This eidetic analysis of the data served to reveal the essential and invariant characteristics of the phenomenon of interest (Gallagher & Zahavi, 2008). Through this process the researcher was able to identify repeating and enduring patterns that were emerging from the data which, in turn, revealed the essential structures of the phenomenon. (N. France, PhD, RN, personal communication, February 21, 2008).



The process of free imaginative variation was employed in order to express the data in meaning units. These units provided a method of coding that involved looking for changes in meaning within the data. Each change identified a new meaning unit. The meaning units were listed to the right of the hand written text and formed a third column.

The meaning units were then organized through coding. The researcher identified themes from within the data and developed codes that were representative of those ideas (Morse & Richards, 2002). This coding and identification of themes provided organization of the data for the more in-depth structural eidetic analysis (Wertz, 2005). The coded data became the transformed meaning units and were listed in the fourth column. The transformed meaning units expressed essential aspects of the phenomenon, more explicitly, in a language consistent with that of the nursing discipline (Giorgi, 1997; Wertz, 2005). This is not to say the researcher deduced ultimate meaning. Rather, through a process of removing context and discerning the essential structure, while ensuring the data guided the findings, elements of the lived experience of women with breast cancer who create art were described.

An excerpt of the interview that was conducted with one study participant is presented in Table 2. The first column displays the text as transcribed verbatim. The second column shows the resultant interpretation done by the researcher. Through a process of imaginative variation, a meaning unit was discerned which is shown in the third column. By adding and subtracting various structures from the interpretation and ensuring that the invariant or essential structure remained, the meaning unit was derived.



The resultant transformed meaning unit was developed in order to be able to convey the essence of the meaning unit within the context of this research.

Table 2 *Imaginative Variation and the Resultant Transformed Meaning Unit* 

Transcript Verbatim from Study Participant Beth	Transcript Interpreted by Researcher	Meaning Unit	Transformed Meaning Unit
OK, it was a year even after that. Where you see the same subject matter. But this time the painting has been framed off center, it's larger, the first one w- the first one is 8 X 10, this one is 12 X 8. And it's much softer looking. I've let go of some of the control and let the paint and the brush do some of it, and leave it alone, allow it to be. And not have the control down to the final thing.	Beth is comparing the artwork she painted prior to her first diagnosis with breast cancer to the paintings she created after the initial diagnosis as well as the second time she was diagnosed with breast cancer. Initially the flowers were painted in the center of the canvas. After dealing with cancer for a second time the same flowers are painted off center on a larger canvas. She has let go of control and allowed the paint and brush to do some of the creating, leaving it alone, allowing it to be.	Let go of control	Attitude

### **Summary**

The rationale for the use of phenomenology in providing a method for describing the lived experience of creating art for women with breast cancer was presented in the preceding chapter. In addition to describing the steps taken to protect participant confidentiality, recruitment and data collection methods were reviewed. The use of Giorgi's (2008) phenomenological process for analysis of the data was examined. An example of the steps taken to discern a meaning unit from within the raw data and the transformation of the meaning unit were provided. Chapter four presents the findings of



this study. Chapter five includes a discussion of the findings along with implications for nursing practice, nursing research, and nursing education.



## CHAPTER 4 FINDINGS

#### Introduction

This chapter presents the findings from the analysis of the qualitative data obtained through in-depth participant interviews. The chapter begins with a bio sketch of each of the four women who participated in the study; pseudonyms were used to assure anonymity and confidentiality. This is followed with a description of the data analysis processes and the resultant transformed meaning units associated with the phenomenon of creating art by women with breast cancer.

## **Description of Participants**

A description of the lifeworld of creating art in the natural attitude of women who had been diagnosed with breast cancer was sought by the researcher. Recruitment efforts yielded a total of four women, meeting inclusion criteria, who agreed to participate in this study. Of them, only one of the study participants began to paint and write poetry art after her diagnosis of breast cancer. The other three had expressed themselves through a variety of creative mediums, which included painting for each of them, prior to their respective diagnoses of breast cancer.

#### Anna

Anna was a soft spoken woman of Filipino heritage. At her request, the interview with her was conducted in her office. Anna was an RN on staff in the student health center of a large state university in central Florida. In addition to photographs of her

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children, her office contained several pieces of her artwork. While apparent that a few of the pieces were hanging in their customary place on the walls, several pieces have been brought in from home for the researcher to see as well. Anna is the single mother of four children ranging in age from eight to 20 years. Anna grew up in a family of seven children. She described each of her three brothers and three sisters as "having talent", whether it was in drawing, singing, or playing the guitar. Other than taking a drawing class in college, Anna reports she had never explored her artistic abilities prior to her diagnosis of breast cancer.

Anna was diagnosed with breast cancer five years ago at the age of 38. After having a mastectomy of the right breast and receiving six rounds of chemotherapy, Anna described how she was moved to begin to create art.

I went through a mastectomy of the right breast and I went through 6 rounds of chemo which took about four months on top of that. After I started feeling better, I started thinking how I can give back, to maybe just the American Cancer Society, how I can, I don't know, do something? What can I do to help other women who went through what I went through and so when I started I said well let me just start painting.

As Anna began to show her artwork to family members, friends and co-workers she began to get requests from them to paint a specific subject. Her son requested a painting of a clown fish "like Nemo" and her daughter asked for a painting of a dancer. The artwork Anna created was also inspired by pictures, such as the photograph of the Geisha woman she saw on the internet.

Anna also began to write poetry after her treatment for breast cancer. Of the fifty or more poems Anna wrote, she reported, "75% of them are pretty dark." When asked



why she views these paintings as "dark", she offered the following description of one of her first paintings.

Oh yes, it was (dark). I didn't bring it because I said, Oh, she is going to look at it and she's going to say, oh, were you depressed? It was a painting of a faceless woman in a really dark room. It's almost like she is in the corner of a bar. Alone, just all to herself. I kept it. I said, because it is something to remember.

Anna went on to describe her use of primary colors in the subsequent paintings she has created. The choice is due, in part, out of necessity because she has not mastered the art of blending colors but also because "it is a matter of what is pleasant to my eyes."

#### Beth

Beth exuded energy as she opened the front door of her home to invite the researcher inside for the interview. The Caucasian woman is petite in stature, and her age is in the sixties. Beth chose to be interviewed in the 800 square foot studio she and her husband added to the family home after her initial diagnosis of breast cancer. She reported she had enjoyed drawing and painting for many years prior to her diagnosis. She is well known in the arts and crafts world for the "how-to" articles she has written and illustrated for craft magazines. Beth also has maintained a website where she sells art supplies. Beth first experienced breast cancer in 2003. She chose to have a bilateral mastectomy and reconstruction at that time.

When I first got breast cancer it was only in one breast but I decided right then and there that I was going to have bilateral mastectomy because I didn't want to play this game again. I thought once was enough.

Beth began to journal about her experiences with breast cancer treatment and recovery in a section of her retail website. The frequency of the regular updates



chronicling her experiences with breast cancer had slowed down until she was diagnosed with a recurrence of breast cancer in 2005. This recurrence stimulated her to resume writing until March of 2008 when she wrote, "I will not be writing on a regular basis anymore since life has returned to 'normal' and all is well." Beth reported she did not have the energy to paint after her first breast cancer diagnosis.

Beth did, however, manage to make a few Christmas ornaments for her radiation oncologist and his office staff. As a result of receiving one of the ornaments, the physician asked her what firing temperature she had used in the kiln to make the ornaments. Beth discovered the physician was an artist as well. This conversation resulted in a collaboration of sharing techniques and working together on art projects that has continued into the present. Beth experienced another change in regard to the art she created as a result of having breast cancer:

Roses are one of my favorite things to paint. The roses I painted in '98 were very nice roses, very structured, not realistic. In 2006 I'm getting better. I'm still tight, still in control. Control and losing my hair were the two things I hated most about having breast cancer. A year after that, you see the same subject matter, but this time the painting is framed off center, it's larger than the first one. It's much softer looking. I've let go of some of the control and let the paint and the brush do some of it and leave it alone, allow it to be

#### Claire

Claire answered the door of her home that is situated in a community located on a barrier island off the Florida coast of the Atlantic Ocean with a warm welcome. She invited the researcher into the home she shares with her husband with a big smile. The walls of the living room and dining room displayed several pieces of her art work. There were also several framed and unframed paintings stacked along some of the walls.



After settling at the dining room table amidst her artwork, Claire began to tell her story. Of Anglo-Saxon descent, Claire reported her age was 75. Upon retiring to Florida with her husband in 1995, Claire started to paint landscapes. Other than being a part owner in a yarn shop for a time in the northeast, she denied having a background in artistic creativity. When she decided she wanted to paint on canvas, Claire reported that she took a couple of classes but could never find a good instructor. Claire earned an honorable mention in an art show for one of the first paintings she created. That made her think, "I can do this."

When we retired and we came down here, I decided I was going to learn how to paint. Come hell or high water and whether or not that turned into anything, I knew I wanted to do it. So I went to the library and I got a lot of books and that's how I learned.

Claire was diagnosed with breast cancer in 2004. Claire's treatment for breast cancer included a lumpectomy for the removal of two small breast tumors followed by radiation therapy as well as chemotherapy.

In 2004, after my diagnosis, I decided I was going to do whatever it took to get through it, whatever I needed to do, but I wasn't going to stop painting then. Which, actually, became my savior through the whole experience. I've never really been sick...I decided this was probably not going to be the best experience of my life, but this was not going to take precedence over how I lived my life.

Claire was not available for intersubjective verification of the findings of this study due to a second diagnosis of breast cancer. When the researcher contacted her to schedule a second visit she reported she had been diagnosed with breast cancer "in the other breast". She was told that this was not a recurrence but a "different type of breast cancer" than the first diagnosis. Claire underwent mastectomy and reconstruction of the left breast in July 2009. Despite a strong desire to meet with the researcher and repeated



attempts to talk on the phone to discuss the analysis of this study, Claire was not "up to it".

#### Diana

Diana is an African-American physician in her sixties specializing in women's health. She chose to be interviewed in a space at her medical practice. Diana recalled replying to an advertisement in a magazine to enter an art contest by drawing an image at the age of 8. The soft-spoken woman reminisced about winning the contest for which the prize was a paint and art supplies kit. Diana reported she had always painted with the exception of periods in her life such as during medical school and her Obstetrics and Gynecology residency when there was no time to paint. Diana proudly announced, "I've been painting ever since."

Diana also reflected on her life as the ninth of twelve children raised in a small Mississippi town in the 1950's. She recounted the segregation she experienced as a result of being a black child growing up during that time.

Race relations were very harsh and brutal sometimes. Actually, an experience with a doctor there is one of the things that spurred me on to become a physician. A traumatic experience I had triggered me to be a doctor who did not look at race, separation of people to determine what type of care I would give that person. As harsh as that reality was, it helped to mold who I became.

Years ago, Diana reported, she was drawing mostly with pencil and crayon and painting with oils. Diana began to look for a new medium when a friend asked her to illustrate a book of poetry the friend had written. Diana rejected the idea of using watercolors because she could not get the bright hue for which she was looking, and oils



were too "clumpy." It was during this period that Diana discovered the airbrush. She reported "I can get the feel to my artwork with an airbrush because I can blend the colors and mix them; I can get them the way I want them."

Diana described her reaction to receiving a diagnosis of breast cancer with the following words.

There is no perfect family. No one has a perfect ride through any of this. Whatever challenges you have as a family, either some of the kids will grow up to be positive and nurturing and giving. Then you're gonna have some who grow up to be selfish and angry as a result of hanging on to whatever negatives were in their childhood. I chose to let all that go and try to understand why it happened, and to understand for myself that I didn't want to be like that. I wanted to be different. I wanted to be more of a person to uplift, where I could, rather than to try to hurt someone. So, actually, having breast cancer was not the most challenging thing I have ever faced. The most traumatic thing that ever happened to me was my mother was murdered.

Diana reflected on the time period since she was diagnosed with breast cancer in 2003, in the following way: "Since that time I've done more thinking about what I want women, in particular, but just people in general, but women to feel and see in the work I do."

# Accessing the Natural Attitude for the Phenomenon of Interest

The lived experience is necessarily a singular encounter with the phenomenon.

Therefore, the interview questions must move the participant from a general representation to a singular experience. Prior to beginning an interview, Petitmengin (2006) suggests using an exercise with the study participant of recalling a memory of a holiday or another memorable event to aid in directing attention to various dimensions of



a particular experience. The researcher then draws on various dimensions of the expressed experience to deepen the description from the participant to the required level of precision. This exercise has also been viewed as useful in establishing rapport between the researcher and the study participant.

In conducting the interviews for this research, the warm up served to pave the way for eliciting the rich description of the phenomenon of creating art from each woman. The goal of the researcher was for the participant to deepen the narrative that described the characteristics of her experience beyond those that were merely chronological. The aim was to obtain thick description of the meaning or essence of the phenomenon of interest (Morse, 1994).

After each participant was relaxed and ready to begin the interview, the researcher asked her to describe, in as much detail as possible, any event that stood out in the participant's memory. The study participant was encouraged to choose an event that had special meaning and significance beyond all others at that very moment. Each woman was further instructed to describe the situation in as much detail, including, sights, sounds and smells, as possible.

Beth provided a detailed account of her experience in attending a Broadway performance of "Phantom of the Opera" with her daughter. The trip to New York, dinner and the tickets to the opera were a 60th birthday gift to her from her family. The researcher was nearly transported to that time by listening to Beth describe the sounds of the orchestra warming up and of being surrounded by the members of the audience dressed in their finest clothes. Claire recounted a trip she had taken to France to take a



Plein Air workshop. Claire explained that "Plein Air" literally translated means "fresh air" and that French impressionist painters were the first to paint in outdoor settings. Claire rendered a particularly compelling description of a street café where she and her friends sat and sipped hot chocolate in the fresh September air. Diana did not hesitate to recount her honeymoon in Cancun during her warm up. One could almost feel the salt in the breeze from the ocean as Diana described standing arm in arm with her husband on the balcony of the hotel where they honeymooned.

### **Data Analysis Processes**

After each interview was transcribed, the transcription was perused in its entirety. In a second more thoughtful reading, the researcher identified meaning transitions in the transcription of each participant interview. Sections of the transcription were highlighted with color coding and transitions within the text were noted with a slash mark. The researcher further transformed the meaning units by re-writing each one in more general terms. The resultant sections of text provided the constituents or essential components that comprise the meaning units. Meaning units and participants' spontaneous discrimination of various aspects of the phenomenon, expressed in their own words are displayed in Table 3.



Table 3
Transformed Meaning Units for Nursing

Contextual	Dynamic	Enduring
Giving Back	Creative Space-	Creative Experience
Positive feeling	Spatial versus Emotional	Builds self esteem
Control over one's life	Close to people I love	Gives one a goal
Awakening of her own	A goal achieved	Saves one
sensuality	Anyplace where there is a	Keeps one on an even keel
	connection to art	Another world to be in
	A state of mind	Reemergence as a woman
	Resurgence of sensuality	Relaxing
	Outlet for emotions	Puts one in a beautiful space
		Strengthens relationships
		Gain control
Individual Journey	Creative Expression	Sense of Self
Trial and error	Journey evolves over time	Nicer
Letting go	Connects things	Give more kindness
Sense of satisfaction	I am emerging	A new normal
Desire to see what happens	Opportunity to edify others	Let go of control
New meaning	In a beautiful space	Determination
		Uplift where one can

# Meaning Units

## Giving Back

Upon each experience with being diagnosed and receiving treatment for breast cancer, all four participants reported a personal need to provide support to others whose lives had been touched by the disease. All of the women in this study expressed a strong need to educate and support others about living well after experiencing cancer. While the motivation for each individual varied and the way in which the artistic expression was carried out differed, the experience of creating art gave each woman an opportunity to "give back" through the art that she created.



Anna reminisced about a strong desire to provide emotional support for anyone undergoing treatment for cancer after she, herself, had breast cancer. Anna also wanted to provide financial support to aid in breast cancer research and education. Her original motive for learning to paint was to sell the paintings she created and to donate a portion of the sales to the American Cancer Society®. As she was creating the pieces she planned to sell she reports a "positive feeling" in being able to give back in that way.

I found other ways of giving back too. It doesn't matter what kind of cancer. I would give that person my number, my name and I would give them the option, you know, if she wants somebody to talk to. I would become moral support, a type of a person a friend. I have done that for three or four people I had never met.

For Beth, there was a need to share anything that she had learned about breast cancer with others. Beth chose to share this information by writing in her online journal located in her retail website.

I'd never paid attention to it because breast cancer didn't run in my family, therefore I wasn't going to have it. So I didn't need to worry about these things. All of a sudden, I did need to worry about those things. And I realized my friends didn't know about it either. So I started writing. Writing the journals seems like an obligation, but I know it's not. It is just that it gives people hope, because you know, they've had other people, who you know have died from it.

Financial support for breast cancer research and education were also important to Beth. She reported that a portion of the proceeds from the sale of the art brushes she sold on her retail website were donated to the Susan G. Komen for the Cure® foundation.

Claire was driven to be involved in helping others, specifically to become involved in breast cancer awareness and education. She has conducted art workshops she calls "Kindergarten for Grown-ups" which give cancer survivors an opportunity for creative exploration.



The purpose is not to be great artists. It is to learn that there is so much that can be done to keep you peaceful, by working with your hands and your head. Just doing something; pretty much mindless.

For each of these women with a history of breast cancer, the experience of creating art was more than an opportunity for them to give back. In addition to the financial and emotional support they were able to provide to others stricken with the disease, there was an intersubjective aspect of the experience as well. The positive feeling each one experienced, on a personal level, as a result of creating and sharing her artwork or creating art with others became more about what they were able to do with the art they created. For these women, the act of giving back through the art or the prose they created helped them to establish an optimistic about their journey with breast cancer.

Contributing financial support gained through the sale of paintings and art supplies, offering firsthand knowledge about the breast cancer experience, teaching others how to create art and creating art that conveys sensuality portrayed a sense of confidence in a positive outcome for each one.

#### Time to Create

Creating art was "trial and error" for Anna when she began to paint after her diagnosis and treatment for breast cancer. She had always viewed herself as less artistic than her siblings were. A single mother of three, Anna worked as a nurse fulltime to support her three school-aged children. Oddly enough, her time at home recovering from breast cancer gave her the opportunity she needed to explore painting on canvas. Though she was not certain she would "be any good at it at all," she enjoyed painting. Anna



experienced a strong need to create art after her diagnosis of breast cancer. To her surprise, her family, friends and co-workers liked her paintings and spurred her on to create more.

It's trial and error, it's like experimenting. It's like would I be good it I try faces? How can I make it look more realistic? Should I just find my own style? Because I find myself looking on the internet, like different styles of painting, I was like, man, I could do so much better than that!

Beth expressed her belief that a lack of confidence and a need to control the art she created held her back from exploring and trying new techniques with her artwork. She reflected, "Perhaps it was a fear of making a mistake or if you don't try you can't fail [that caused her] to stick with the same formula. . . without changing anything it is always going to have the same result." After her second diagnosis of breast cancer, Beth no longer desired the same result each time she created a painting.

I did think about things a lot, about what I wanted to change. If I made it through all that[breast cancer], was I going to go back to doing the same thing? Or was I going to actually do some of those things that I'd always thought about?

Even though Claire had been painting for ten years prior to her diagnosis of breast cancer, she too spoke about artistic ability and the importance of not letting the perceived lack of ability hold one back. This idea was the impetus for the workshops that Claire cosponsored with other area artists.

For this group of women, taking the time for artistic exploration was borne of the experience of each one with breast cancer. For one woman, a desire to explore her artistic abilities came as result of being removed from her busy schedule of a single mother who worked full time. For yet another woman who had been expressing herself through



writing and painting for years, a second bout with breast cancer brought about an experience of wanting to "explore" to try new creative endeavors without having the boundaries she had placed on herself previously. The third woman related the importance of taking the time to remove one self from everyday life and to do something like creating art.

#### Creative Space

Anna painted in the family room of the home she shared with her three school-age children. She did not find their presence distracting. On the contrary, she indicated that she enjoyed having her children nearby when she was painting. She was available to answer their questions about homework while receiving the children's critique of her artwork.

I like being close to people that I love, that I cherish, and at the same time doing something that I love. My living room is brighter. I guess, subconsciously, I didn't want to stay in the bedroom because that is where I was for the most part when I was sick from chemo.

For many years, Beth had painted in the guest room of the modest ranch style home she shared with her husband. After her first diagnosis of breast cancer, she and her husband asked each other, "What are we waiting for?" Beth describes the realization of the goal of having an art studio was important in that it gave her "something to look forward to" during those months of treatment for cancer. With that, work began on the addition of an 800 square foot addition to their home. The walls of the large space were lined with windows that poured light into the room that doubled as retail space and art studio. The walls also contained shelves filled with paints and brushes, cabinets



displaying Beth's artwork as well as inventory for her retail art business. Tables and easels scattered throughout the studio provided generous space for creating art in one of several media Beth employs.

Like Beth, Claire had been using whatever space she could to create her paintings. Plans were already underway for a contractor to convert a second bedroom into an art studio when she received her diagnosis of breast cancer. Claire described the insatiable need to escape the realities of her diagnosis by going into her art. Whether she was outdoors, at the beach or at a friend's home, she sought creative space.

I never stopped painting. When the contractor was working in the studio and I couldn't paint, I would sketch. On the days that I felt crappy, and there were many, I tried to find a place to hide so I could either read about art or do something connected to art.

For Diane, creative space was not described by the physical aspects but by an intellectual facet. The creative space that Diana described was illustrated as a state of mind, "a beautiful and relaxing place". Diana provided yet another facet of the effect of the phenomenon. For her, creating art was relaxing.

I paint to relax the other half of my brain--to strike a better balance between the artistic part of my brain and my being. It puts me in a beautiful space. Creating art has helped me to strengthen my relationships and to recognize what is really important.

Creative space was described in a physical sense as well as from a cerebral perspective by the study participants. Whether in a central room of the house, surrounded by children; outdoors because the home was under renovation; in a second bedroom or in a large, studio bathed in sunlight the physical description of creative space varied.



Defined less by the material attributes, creative space as described by these women was a state of mind where relaxation and escape became possible.

## **Creative Expression**

Beth reports a lack of interest in creating art after her first diagnosis with breast cancer and during treatment.

It [Adriamycin] tried to kill me you know. I could not even pick up a book. I was not interested in trying to paint anything. I didn't have any energy. I did not care. I lost my hair, I looked like an alien. There was nothing to inspire me to paint. It would have been all black if I would have done something like that.

While Beth did not create any art during the early days after her first diagnosis with breast cancer another woman never stopped drawing. Rather than focusing on how she felt in the early days of treatment, Claire describes "getting through it" by reading about art or sketching. As opposed to centering on her feelings or the fear connected to the breast cancer experience, art "took her to another place". In referring to the paintings she created in the early period after treatment for breast cancer, Claire describes them as "awful".

I got these huge canvases, three by four feet. I did these huge marsh scenes and street scenes. They were life-extending for me. It was probably a form of mediation. I disappeared into all of these places. I don't think I could have gotten through, which I call sailing through, without having either a paintbrush or charcoal and a sketch book to go out and do what I did. It gave me another world to be in. I would focus so much on what it takes to compose a painting that I would just disappear.

In addition to expressing herself artistically through painting, Anna wrote poetry during the first weeks after her diagnosis of breast cancer. In describing those poems she wrote and the paintings she created during that time she said,



I probably wrote 55 different poems. I look back and realize that 75% of them were pretty dark. One of the paintings was of a faceless woman in a really dark room. It's almost like she is in a corner of a bar. She was alone and all to herself. I kept it because it is something to remember.

Neither of the women spoke fondly of the paintings done during that time. Both women did express an awareness of the importance of creating art to their journey with breast cancer during those early days.

Clearly, the creation of art provided an avenue for these women for expressing the emotions and the deep-set feelings each one was experiencing. While one woman described that time as being so dark that she was unable to create art, two others recalled the experience of creating art during that time quite differently. For the latter, writing poetry and painting was a way to reflect on the lived experience, a way of escape and a means of accessing an extension of one's life that went beyond the present.

Creating art began at an early age for some of the women in this study and in later years for others. Each woman's personal journey in dealing with breast cancer and creating art evolved over time. Anna was surprised at the paintings she was able to create when she began to paint. She was further amazed when friends and co-workers showed their appreciation of her artwork by commissioning her to render paintings of particular subjects. She reports it makes her "happy" to create paintings for others. Beth described the experience of creating art for herself as "feeling as if I am emerging." She further explained, "I don't know out of what—I know I am not done." Diana's experience with breast cancer caused her to want to "be more of an individual that edifies where possible." She describes the feeling she gets from creating her paintings as "putting herself in a beautiful space whenever she is creative".



During the interview with the researcher, Beth showed several examples of artwork created prior to her second diagnosis with breast cancer. She contrasted the paintings to that of the same subjects painted several years later. Two examples displayed in Figure 1 show irises painted in 2004 and then again in 2008.



Figure 1. Contrasting 2004 (left) and 2008 (right) paintings created by cancer patient.

The flowers in the earlier version are well defined and structured. "Tight" and "controlled" are the words used by the study participant to describe the older painting. The second painting of the same flowers contains less definition and is softer in appearance. The study participant announced "I let go of the control. I let it be softer, let it not be so tight." The evolution in her artwork for one woman was that of using her artistic ability to elevate and edify others.



#### Sense of Self

The women remarked on how they were affected by the diagnosis of breast cancer and the ways in which the creation of art mitigated the effect. Anna said, "I found myself being nicer, giving more kindness." Beth said she was "back to normal, but it's a new normal." In regard to the effect having breast cancer has had on her art she said, "I've let go of some of the control. Let the paint and brush do some of [it] and leave it alone."

Claire elaborated further, "I decided I was going to do whatever it took to get through it. I was not going to stop painting." She added, "I think determination has a lot to do with how you cope with the treatment for breast cancer."

Diana commented, "I wanted to be more of a person to uplift where I could rather than hurt." For Diana, a need existed to convey, through the paintings she created, the essence of continued sensuality and sexuality for all women who have received treatment for breast cancer. Diana described experiencing an awakening of her own sensuality as she conceptualized and chose the colors she would use to create each painting. She reported continuing to experience that sensuality while was she creating the paintings as well as when she would look at them afterwards.

"When we are going through that journey with breast cancer, of course our breasts are representative of that sexual part of ourselves, our attractiveness."

#### The Creative Experience

Anna described her experience with creating art as "bringing a lot of positive things. . . it brings me joy to share my art. . . using bright colors in my art brings smiles to people's faces." Anna further elaborated by saying painting "connected things" for her



and "built my self esteem and gave me a goal." Anna was grateful to have survived breast cancer and to be alive. She exclaimed, "Let me do something I've never done." Beth had become more open to suggestion than she was before her experience with breast cancer.

In addition to her artwork giving her "another world to be in," Claire credited her perseverance in continuing to paint through the diagnosis of and treatment for breast cancer as instrumental in giving her 'control over my life'.

Saved my life and kept me on an even keel. There is so much that can be done to keep you peaceful by working with your hands and your head. I was at peace while it took me away from the bills and the nature of scrubbing my apples. It allowed me to disappear in all these places. It gave me another world to be in.

Diana described experiencing a resurgence of her sensuality as a woman through painting. "There was an awakening of my sensuality; it allowed me to go through my own re-expression, reemergence as someone who could have a positive self-image."

So you are walking around connected to this drain and you've got this dressing. You can't feel real sexy when all that is goin' on. You've got to worry about how your partner is going to accept you sexually after going through all of that. I wanted to highlight and for women to have a sense, when they look at the artwork that I do, is that you go through all of that but you still maintain the essence of your sensuality and sexuality. It may have a temporary decline, but then you have resurgence in that part of you as time goes on. I have had several women tell me when they looked at a piece they really felt for the first time that they could be sexy again. I have actually walked through those feelings myself.

While another woman had been drawing and painting since childhood, the feelings she expressed through the paintings she created after her journey with breast cancer had a new meaning.

For Beth, giving up control and allowing her artistic expression to evolve was described as one aspect of her lived experience of having breast cancer. However, Claire described a sense of gaining control through her painting after her diagnosis with breast



cancer. For the latter, the art she created gave her a sense of control and a goal toward which she could strive as she was struggling with the breast cancer diagnosis and the resultant treatment and therapy. Claire also described her experience of creating art after her diagnosis with breast cancer as having "connected things" and keeping her "on an even keel". Anna credits the experience of painting after her diagnosis of breast cancer with building her self esteem and self-confidence, "reemerging as a woman" and strengthening her relationships, was viewed as an effect of creating art for another woman after her diagnosis of breast cancer.

# **Transformed Meaning Units for Nursing**

The researcher cross checked the structure of the phenomenon derived from the transformed meaning units with the data to ensure that all key constituents were included. Imaginative variation was again employed by the researcher in order to determine which transformed meaning units typically were essential to the appearance of the phenomenon of creating art by women with breast cancer (Giorgi, 2008). Essential structures consist of those elements that are necessary for an experience to present itself as what it is (Polkinghorne, 1989). Rather than attempting to define structures of the phenomenon that were universal, the researcher sought to develop a composite that described the lived experience of creating art for women with breast cancer (Giorgi & Giorgi, 2003). That is to say that these universal findings held true for this group of women. Organizing the data in this manner was useful in that it permitted a description not only of the key constituents of the phenomenon but also the relationships and variations among them.



The next few paragraphs discuss the elements that emerged from the interviews with women in this study, specifically, contextual, dynamic and enduring constituents with associated meaning units for each category.

The transformed meaning units provided the structure for the description of the phenomenon. The first goal of conducting the transformations was to change the experience that was implied by the study participants to the explicit with respect to nursing science. In doing so, the researcher was able to generalize the lived experience so that the description was less specific to this group of women.

Three distinct categories or variations of the essential elements that comprise the structure of the phenomenon under study emerged from the transformed meaning units.

Table 3 shows a summary of the transformed meaning units described by these four women. Constituents of the meaning units are grouped within clusters which were entitled: contextual, dynamic and enduring.

#### Contextual

Contextual constituents were described as those elements that were presented as essential in creating art for these women with breast cancer. The contextual constituents 'Giving Back' and 'Time to Create' provided a background descriptor for the experience of creating art for these four women.



## Giving Back

While receiving a diagnosis of breast cancer and submitting to the medical treatment was a situation each found herself facing, each one chose a method of answering her circumstance by taking action. One woman described the positive feeling of giving back through the donation of a part of the proceeds from the sale of the art she created. For another, writing about her cancer experience in a blog was a natural response to her breast cancer experience. She felt gratitude for the positive results she had from her treatment and as well as a sense of duty to share her experience. She believed that reading her words may help to make another's journey with breast cancer a little easier. Teaching others how to paint or to explore creative expression was described as helping others to realize the benefits she had known from creating art during her own breast cancer experience for yet another. Creating art that depicted a woman's sensuality after a diagnosis with breast cancer helped the fourth woman to feel as if she had regained a part of her womanhood that had been damaged. Each woman described this part of the experience of creating art as one of taking action. For each, in a way of her own, the action of giving back gave meaning to the experience with breast cancer for each woman.

#### Time to Create

Described as an escape from the realities of the woman's life, she found the experience of creating art to be an opportunity to get away into the art she created.

Creating art was an opportunity to try something she had never undertaken before and to experience a feeling of accomplishment. One woman described a feeling of "life"



extending" in painting on the large canvases after her breast cancer diagnosis. More than merely a distraction, the product of the creative endeavor serves as an extension of the woman. Her artwork became a reminder of her existence for all time.

## Dynamic

The evolutionary characteristic of the dynamic constituent was invariant for this group of women. The lived experience of creating art was described as evolving for each woman. Whether beginning during childhood or taken up in adulthood, the experience of creating art was evolving for each study participant.

The attributes of the phenomenon that were described by the study participants in varying degrees or at different levels were termed dynamic constituents. 'Creative Space' and 'Creative Experience' encompass the facets of the dynamic constituents.

#### Creative Space

The physical perspectives of the space in which the women created was shared by all but one of the study participants. One woman described a feeling of connectedness when painting in the midst of her children. While a large space was certainly an advantage, two of the women in this study shared their experiences with creating in small and cramped spaces. For each of them, the relaxing feeling that would overtake them as they immersed themselves in their creations was described as transporting them to a different space. Another woman described her creative space as that of striking a better balance for herself. She describes a sense of relaxing her brain when she paints.



## Creative Expression

For the women in this study, creative expression took many forms. While most of the women used a brush to paint on canvas, one woman developed her own technique of painting with an airbrush. All of the women expressed their creativity in a variety of ways. Writing poetry and journaling about her experience with breast cancer on a blog provided a creative outlet for two of the women. Sketching with charcoal was described as well. One woman described planning her garden, planting the flowers and plants and caring for the area of her backyard as expressing herself artistically. In spite of the form of creativity, each woman described a feeling of being able to express themselves through a creative outlet in ways unlike any other method known to them.

#### **Enduring**

Enduring constituents comprised the most fundamental aspects of creating art and were shared by all four of the study participants. The "Creative Experience" and "Sense of Self" encompass the enduring constituents.

## Creative Experience

This group of women described positive feelings in all aspects of the creative experience. The joy they felt while creating their artwork was increased only by the acceptance and appreciation they received from those who viewed the work or received the piece of art as a gift. They further described experiencing a "connecting" of aspects of their lives through the creation of their art as well. In addition to being transported to a



place other than the reality of the circumstances of their life and their state of health and healing, these women described a method of communicating their feelings through the art they created.

#### Sense of Self

All of the study participants noted a change in attitude as a result of creating art after having been diagnosed with breast cancer. Whether finding herself being more pleasant or giving more kindness, each woman looked for ways to uplift others where she could. Several of the women spoke about the determination they experienced through creating art as a result of having had breast cancer. For some, control emerged as an attribute of attitude.

## **Summary**

In summary, this chapter presented the findings of the data obtained through interviews with four participants with a diagnosis of breast cancer who create art.

Chapter 5 contains the findings with implications for nursing practice, nursing education, and nursing research.



# CHAPTER 5 FINDINGS, CONCLUSIONS, AND IMPLICATIONS

#### Introduction

This chapter contains the findings from this exploratory study that focuses on the creative art experience for women with breast cancer. Recommendations for nursing practice, nursing education, and nursing research are examined along with the strengths and limitations of this study.

## The Lived Experience of Creating Art

Coping with a life changing event like breast cancer often includes an innate desire to demonstrate gratitude for having survived. For one study participant, Anna, a portion of the proceeds garnered from the sale of her art work provided the vehicle for giving back on a financial level. Writing about the breast cancer in the form of an online journal provided a forum for sharing the experience for yet another study participant, Beth. Sharing firsthand knowledge about the situation to help someone else somehow makes living through the experience worthwhile for the individual.

Whether initiated during childhood or well into adulthood, the experience of creating art holds benefits for the creator beyond approval from others. Though accolades from others are appreciated, the true benefit of creating art appears to come from within the individual. Whether the artistic undertaking will be viewed as valuable or pleasing in the eyes of others symbolizes the relinquishing of control over one's life. Creating art



offers an opportunity for an individual to get involved, to go beyond the confines of one's immediate existence and to explore.

Choice of space that participants used for their creative expression was driven primarily by availability. The setting need not be a large space dedicated solely to artistic endeavors but often has multiple functions. An area large enough to assemble the needed materials appears to be all that is required for the creation of art.

The process of creating art serves as a form of meditation for some individuals. Whether in the form of gardening or painting, the creative outlet provides a spiritual transcendence for the individual. As the focus of attention is on the art making and artistic expression, a rising above one's day to day realities takes place. More than a distraction, creating art provides an opportunity for self-expression and re-emergence on a spiritual level.

Cameron (1992) referred to the transcendence experienced by one through artistic expression in terms of 'spiritual electricity'. The act of creative expression transports the artist into another world. Described as putting one into a beautiful space, the experience builds self esteem while giving the individual a goal to be accomplished. These findings are supported by the results of research conducted by Heenan (2006) in a community-based mental health program in Northern Ireland. While the population under study varied from that of this research, the respondents reported improved self-esteem and self-confidence after creating art. In addition to providing an opportunity for relaxation, there was a smoothing out of the rough edges of life that occurred for this group of individuals through creating art.



There is both a gaining and a giving up of control that occurs for the individual when creating art. Rather than attempting to assert control over past or future life events, one is given an option to levy control over the creative aspect of her existence. This concept is supported by a qualitative study that sought to describe "not giving in" for a group of breast cancer survivors (Jensen, Back-Pettersson, & Segesten, 2000). For the women in this study, the constituents of the structure of "not giving in" were described as accepting the challenge to go on living, working actively in the healing process, finding something important to live for, gaining insights about life itself, experiencing awareness and avoidance, and introducing radical changes in the lives of the study participants.

Having a social connection with others who share an experience like breast cancer has been associated with positive adjustment to the illness (Holland & Halahan, 2003). The ability to share concerns with others who have similar experiences decreases a sense of separation from the "normal world". Along with the creating of visual art, writing about one's experience with breast cancer in an online journal provides an opportunity for a creative outlet as well as for a social connection with other women who have dealt with breast cancer.

Beth began writing emails to acquaintances who had inquired about her health after having been diagnosed with breast cancer. The response to those writings was great. In addition, she received multiple requests to send the writings to other interested individuals. Beth decided to post the writings about her experiences with breast cancer on her retail website for anyone who was interested to read them. She reflects that this provided her with an opportunity to share what she had learned as a result of having



breast cancer. Beth employed humor in her writings and entitled the section of her

Website "The BC Journals or How Humor Got Me Through It". She wrote about her

experience with breast cancer and treatment as well as the side effects of the treatments.

Beth posted pictures she had taken of objects that are common to the medical treatment

of breast cancer such as the infusion port that was placed in her chest for the

administration of chemotherapy and the large machine that is used to obtain computed

tomography (CT) scans. She reminisced about a psychotherapist who discouraged her

from writing about breast cancer. According to Beth, the therapist thought the writing

"kept it in the forefront of my mind". Beth proudly stated, "I couldn't not do it. It was an

assignment."

Writing about her experiences with breast cancer and posting them to a blog has the potential to provide a creative outlet Beth. As the World Wide Web gained momentum in the 1990s, there was such a vast proliferation of information on the web that finding information became increasingly difficult and time-consuming (Blood, 2002). Kennedy (2004) described weblogs as web sites on which one or more individuals publish personal opinions, commentary, thoughts and essays with links to other information of interest to the reader. Maintaining a blog is a creative way for women to connect with one another, educate and share their experiences with breast cancer.

A change in attitude occurs for women with breast cancer who create art. The women in this study were filled with determination to live life to the fullest, to extend kindness, to uplift where they were able and to be the best they could be. A similar adjustment in attitude was described by the women who participated in an exploration of



coping resources for women with cancer conducted by Schneider, Fletcher and Snider (2008). The researchers grouped the coping strategies reported to them by the study participants into three groups: Intrapersonal, interpersonal and extrapersonal resources. The intrapersonal resources described by the women were: power of the mind, positive thinking, spirituality, and empowerment through personal control.

The lived experience of creating art for this group of breast cancer survivors presented an opportunity for each of them to give back. Regardless of individual ability or available space in which to create, these women discovered a sense of self as a result of creating art. The women in this study described their art as evolving as a result of having had breast cancer. One woman had not painted before her bout with breast cancer; another found her paintings less controlled and more realistic; and a third woman found the paintings she created tended to be more sensual as a result of wanting to express her own sexuality. The effect of creating art was described as connecting things, building self esteem, having a goal, saving, and remaining on an even keel while transporting one to another place that that was relaxing and beautiful. The phenomenon of creating art was credited with strengthening her relationships for one study participant. Creating art was both giving up control over the parts of life over which one had no power and gaining some control through the art that was created.

## Methodological Strengths and Limitations

The limitations of this study relate to the small sample size and memory recall by the participants of their experience of creating art. Only four women located in central



and the east coast of Florida responded to calls for participation in the study. The possibility of imprecise or erroneous recall on the part of the study participant limits the conclusions of this dissertation. The phenomenological approach to qualitative research relies on obtaining the description of the lived experience from within the natural attitude of each study participant in as much detail and rich description as is possible. There was a potential that one or more of the study participants may have forgotten some aspect of the phenomenon in the time between having the experience and relaying that experience to the researcher. A lack of congruent insight between the study participant and the researcher into the woman's description of her experience may have hindered the researcher's ability to accurately describe the phenomenon.

While the goal of qualitative research is not to generalize the results to a population beyond the study participants, this researcher did seek an outcome that would serve to inform nursing science about the phenomenon. The description of creating art for this small self-selected sample of women with breast cancer coupled with the limited geographic area from which the study participants were recruited may reduce the application of the findings to a broader range of the population. However, there is potential for transferability of the findings. The lived experience of creating art for these four women certainly may be true for other women with breast cancer and potentially for other populations as well.



# **Implications and Conclusions**

The findings from this phenomenological study focusing on the lived experience of creating art for women with breast cancer has implications for nursing practice, education, and nursing research. The description of the lived experience of creating art for women with breast cancer will be disseminated by the researcher through poster and podium presentation at the state, regional and national levels. Publication of the research findings in qualitative research nursing journals will add to nursing knowledge as well as to that of other disciplines interested in holistic approaches to patient care.

# **Nursing Practice**

The structure of the phenomenon of interest by women with breast cancer in this dissertation suggests that creating art is healing. To heal or to make whole again implies that an event or action has occurred that has had an initial negative impact on the total. The result is a change that leaves one changed in some way. In the words of one of the participants in this study, "When you have the scars and you have the breast that's missing, that part of us takes a hit."

While the women in this study spoke of embracing an interest in creating art at various times in their lives, each one spoke explicitly to the positive experience of creating art after a diagnosis and treatment for breast cancer. The descriptions each one provided of creating art suggest the creative art experience is healing. Most notably, creating art gave each woman an avenue for self-expression. Two of the women spoke very openly about the "dark" element of the poetry one wrote and the paintings both of



them created for a time after their diagnosis with breast cancer. The ability to express these negative feelings through creative expression and to be able to move beyond them serves as an example of the healing that can occur.

Nurses are in a unique position to facilitate the creative art process for themselves and their patients. Whether providing care at the bedside in an acute care setting, in a community clinic, or in a provider's office, the nurse has an exceptional opportunity to identify the needs of the patient. Through the use of the nursing process, nurses can employ nursing interventions that incorporate creative expression. This approach to patient care can be viewed as an aspect of a holistic plan of care. Awareness on the part of the nurse of the potential benefits of creative expression is integral to facilitating the activity for the client or the patient. Nurses may elect to explore creating art for their own benefit as well. The nurse needs only to have an open attitude toward the advantages of using creative expression to provide a vehicle for self-expression and for making meaning of life circumstances for themselves and for their patients.

Facilitating artistic expression for the patient begins with the nurse's own journey with creative art. Those who assist others in creating art are encouraged to embark on an exploration of their own experience with creating art (M. Rockwood-Lane, PhD, RN. personal communication, April 13, 2007). The nurse is in an ideal position to facilitate creative expression with patients through discovery of personal artistic abilities, talents and interests. While not mandatory that the nurse participate in creative experience, the creative outlet can be as beneficial for the health care provider as for the patient.



# **Nursing Education**

The findings of this study also have implications for the education of all health professionals and nurses in particular. As suggested by the women in this study, one does not need an art studio or a space with specific requirements in which to create art. Clients living in large metropolitan areas or in rural settings are equally able to create art. Among the education needs for those interested in creating art are the identification of the desire on the part of the individual and the reassurance that it is not possible to make a mistake when creating art.

The researcher has been introducing exploration of creativity for students in the undergraduate courses taught at the College of Nursing at the University of South Florida. Students of all ages, genders, cultural and demographic backgrounds choose to participate in this optional activity each semester. The materials are inexpensive and the instruction is minimal. The researcher participates in the creative art experience with the students. Excitement and, perhaps, a small amount of anxiety can be heard in their voices as they choose their medium and begin to settle in. Shortly, the only sound in the room is coming from the tape of meditation music that is playing on the portable device. On occasion, students who have not completed their project at the end of the time ask to take the materials with them so that can finish their artwork. Many students have given their artwork to the researcher to be placed on display. Still others take their projects with them. These sessions have proven to be an ideal setting in which to introduce the idea of creating art to tomorrow's nurses. Creative expression can be a healing modality for themselves and for the patients for whom they will provide care.



## Nursing Research

There is a paucity of research that describes the effect of creating art after receiving a diagnosis of breast cancer. Is the lived experience of creating art different for the woman who is newly diagnosed when contrasted to the description provided by women who were diagnosed with breast cancer several years before? Is the lived experience of creating art for women receiving treatment for breast cancer different from that of women whose treatment is ended?

Much of the research focused on better understanding the benefits of creating art has been conducted by art therapists with participants who have a behavioral health related diagnosis. As previously noted, the exemplar for this study, "Ginny" was painting with watercolors while receiving chemotherapy for breast cancer. Would another woman who was receiving chemotherapy for breast cancer and painting have the same experience as a result of creating art while receiving chemotherapy?

The possibility of having additional or different outcomes exists for women with breast cancer who create art in a group setting. This potential suggests a need for further exploration into describing the effect of and benefits of creating art in a group. A longitudinal study may provide an opportunity to overcome the limited participant response and short timeframe experienced in this study.

Mind-body Complimentary and Alternative Medicine (CAM) in general, and specifically creative artistic expression, provides the potential for another avenue of support and relief for women with breast cancer. The scarcity of research to date that empirically validates the appropriateness of this type of CAM poses a potential shortfall



in the ability of nurses and other disciplines working within the health sciences to recommend suitable adjuvant treatment options to their patients in general and specifically for women with breast cancer.

Further exploration into body image, sexual roles and emotional reactions of women treated for breast cancer is needed. This dissertation identified one woman's struggle with body image and feelings of the loss of sensuality after treatment for breast cancer. Future research has the potential to provide a better understanding of the beneficial effect of creating art for these women and their identity as a woman.

## **Summary**

This dissertation explored the lived experience of creating art as described by four women with breast cancer. Chapter one discussed the background of the dissertation which provided an historical overview of breast cancer treatment modalities. The researcher's personal interest in the dissertation topic was reviewed. Chapter two included a literature review of the evolution of the use of art first, as a psychiatric treatment method, then that of a healing modality. Research conducted to explore the benefits of creating art for other than women with breast cancer was presented as well as research with women with breast cancer who created art. Chapter three highlighted the qualitative method of research that was used to conduct this study. An overview of Giorgi's method of analysis and the use of eidetic variation was explored as well.

Recruitment efforts, data collection procedures, the interview process undertaken with each study participant and the steps to enhance quality of the data were recounted also.



Chapter four included the analysis of the data obtained from the study participants. The transformation of the meaning units obtained from the data that served to describe the lived experience of creating art for women with breast cancer was explored. The transformed meaning units: giving back, time to create, creative space, creative expression, the creative experience, and sense of self became the structure of the phenomenon of creating art. The final chapter presented the relevance of the research findings in application to nursing education, nursing practice and nursing research.



## APPENDIX A UCF INSTITUTIONAL REVIEW BOARD APPROVAL





University of Central Florida Institutional Review Board Office of Research & Commercialization 12201 Research Parkway, Suite 501 Orlando, Florida 32826-3246 Telephone: 407-823-2901, 407-882-2012 or 407-882-2276 www.research.ucf.edu/compliance/irb.html

#### Notice of Expedited Review and Approval of Requested Addendum/Modification Changes

From: UCF Institutional Review Board

FWA00000351, Exp. 6/24/11, IRB00001138

To: Laurie L. Stark

Date: October 14, 2008

IRB Number: SBE-08-05698

Study Title: A Phenomenological Study of the Lived Experience of Creating Art in Women with Breast

#### Cancer

Dear Researcher

Your requested addendum/modification changes to your study noted above which were submitted to the IRB on 10/10/2008 were approved by expedited review on 10/13/2008.

Per federal regulations, 45 CFR 46.110, the expeditable modifications were determined to be minor changes in previously approved research during the period for which approval was authorized.

Use of the approved, stamped consent document(s) is required. The new form supersedes all previous versions, which are now invalid for further use. Only approved investigators (or other approved key study personnel) may solicit consent for research participation. Subjects or their representatives must receive a copy of the consent form(s).

This addendum approval does NOT extend the IRB approval period or replace the Continuing Review form for renewal of the study.

On behalf of Tracy Dietz, Ph.D., IRB Chair, this letter is signed by:

Signature applied by Joanne Muratori on 10/14/2008 01:13:55 PM EDT

IRB Coordinator

Internal IRB Submission Reference Number: 004073

anne Muratori



## APPENDIX B COVER LETTER



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Date	
Dear Ms	

I am a doctoral student at the University of Central Florida, College of Nursing. As part of my dissertation, I am conducting interviews, the purpose of which is to learn more about the lived experience for women with breast cancer who create art. Your name and contact information has been given to me by someone in a doctor's office, healthcare facility or someone in the community who thinks you may be interested in knowing more about this study. As someone who has had a diagnosis of breast cancer and creates visual art, I am inviting you to participate in one or more interviews. You must be 18 years of age or older, be able to read and speak English and willing to participate in the study. The length of time each interview will last will be an hour or two, that will depend on you. You will not have to answer any question you do not wish to answer. I will audiotape the interview. Only I will have access to the recording and the transcribed information. The recording and the transcribed interview will be destroyed upon the completion of the analysis of the recordings.

I will contact you by telephone a few days after your receipt of this letter. If you are interested in participating in an interview, I will mail you an informed consent. Upon receipt of your signed informed consent, I will call you to set up an interview appointment that will take place at a time and place that is mutually convenient. I will meet you at that designated interview time and place and will ask you to describe your experience with creating art.

If you have any questions about this research project, please contact me at (407) 488-5658 or the chair of my dissertation committee, Dr. Angeline Bushy at (386) 506-4032 or by email at abushy@mail.ucf.edu. Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (IRB). Questions or concerns about research participants' rights may be directed to the Institutional Review Board Office, IRB Coordinator, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246. The telephone numbers are (407) 823-2901 and (407) 882-2276.

Sincerely,

Laurie Stark, RN, MS Doctoral Candidate University of Central Florida College of Nursing



# APPENDIX C INFORMED CONSENT FORM



#### CONSENT TO PARTICIPATE IN A RESEARCH STUDY

You are being asked to participate in one or more <u>interviews</u>. Your participation is voluntary.

Your decision whether or not to participate will have no effect on the quality of your medical care. Please ask questions if there is anything you do not understand.

<u>Title of Interview:</u> A Phenomenological Description of the Lived Experience of Creating Art in Women With Breast Cancer

### What is the purpose of the study?

The purpose of the interview(s) is to describe the experience of women who have had a diagnosis of breast cancer and create art. You were selected because you have been diagnosed with breast cancer and began to participate in the creation of a form of visual art at some point after the diagnosis.

#### What does the study involve?

If you choose to participate in this study, your participation will include an interview in which you will be invited to discuss your experience with creating art. The interview is designed to describe the lived experience of women with breast cancer who create art. It is anticipated that there may be more than one interview. The length of time each one will last will be dependent on you.

#### What are the risks involved with participating in this study?

- Breach of confidentiality: All information you provide will be kept confidential to the fullest extent possible. Your name will not be linked with your responses to questions. This consent form, as well as notes from your interview will be stored in a locked cabinet, accessible only to Laurie Stark, for the duration of the project: six years. The results of this study may be shared with other health professionals and reported as group data and therefore no individual names will be associated with any such reports. Your name will not be used in any publication that may result from this study.
- Mental health discomfort: It is possible that you could feel some mental health discomfort in response to some of the conversation during the interview. You do not need to respond to any questions that are bothersome to you. Completing the interview might make you feel slightly tired, but you can choose to stop and resume completion of it at another time. If you should experience any distress during the interview or as a result of the interview you are encouraged to seek follow up treatment with your primary care physician.

#### Are there any benefits from participating in this study?

You may find it helpful to reflect on your thoughts and feelings about your breast cancer and current life status, although it is not guaranteed this will happen. The information received from you and other study participants will be utilized to write a manuscript on the lived experience for women with breast cancer who create art. None of the participants will be identifiable by the information that is received from the interviews and will serve to contribute to the combined data of the final manuscript. Data from the interviews will be analyzed and the findings will be distributed in professional journals and/or meetings. However, no identifiable information will be used. A copy of the final manuscript will be made available to you at your request.

### Is there other treatment available?



This study does not involve any medical treatment. Alternatives to participation in this study might include participation in a group discussion of the lived experience of creating art for women with breast cancer offered in your community. You may choose not to participate in this study at any time. There are no consequences of withdrawal from participation. If you choose not to participate, your usual course of medical care will continue

### Other important items you should know:

- Cost: You will not be paid for your participation in this study, nor is there any cost to you.
- **Injury:** Should you be injured as a direct result of participating in this research project, you will be encouraged to seek medical treatment from your primary care provider. You will not receive any injury compensation. You should also understand that this is not a waiver or release of your legal rights. You may want to discuss this with Laurie Stark before you enroll in this study.
- **Withdrawal from the study:** You may decide to stop participation in the study at any time. There is no penalty for discontinuing participation in the study.

## Who should you contact with questions about this study?

Questions about this interview may be directed to the researcher in charge of the interview: Laurie Stark at (407) 488-5658. You may also contact Dr. Angeline Bushy, PhD, RN, Professor, University of Central Florida, College of Nursing at (386) 506-4032 or at abushy@mail.ucf.edu.

Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (IRB). Questions or concerns about research participants' rights may be directed to the Institutional Review Board Office, IRB Coordinator, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246. The telephone numbers are (407) 823-2901 and (407) 882-2276.

## **CONSENT**

I have read the above information about the study of the lived experience of women with breast cancer who create art and have been given an opportunity to ask questions. I have been told of the risks and discomforts and possible benefits of the interview. I agree to participate in this interview and I have been given a copy of this consent document for my own records.

Participant's Signature and Date
Participant's Address



## APPENDIX D CONSENT TO PHOTOGRAPH



#### **CONSENT TO PHOTOGRAPH**

You are being asked to consent to having your artwork photographed.

Your decision whether or not to allow your artwork to be photographed will have no effect on the quality of your medical care. Please ask questions if there is anything you do not understand.

<u>Title of Study:</u> A Phenomenological Description of the Lived Experience of Creating Art in Women with Breast Cancer

### What is the purpose of photographing your artwork?

Allowing others to view photographs of your artwork may aid in describing the lived experience for women with breast cancer who create art.

### What is meant by photographs of your artwork?

The term "photograph" applies to still photography of your artwork and the display of those photographs. No photographs will be taken of you.

#### Important items you should know:

- Confidentiality: Your name will not be linked to the photographs of your artwork.
- **Cost:** You will not be paid for photographs taken of your artwork. Your artwork will be not be sold or used in any way to provide financial gain for Laurie Stark, the University of Central Florida or the College of Nursing.
- **Publication:** Photographs of your artwork may be published as an illustration that augments the findings of this study. The photographs may be used, edited and reproduced in any form I order to share the findings of this research project.

#### Who should you contact with questions about this consent?

Questions about this consent may be directed to the researcher in charge of the study: Laurie Stark at (407) 488-5658. You may also contact Dr. Angeline Bushy, PhD, RN, Professor, University of Central Florida, College of Nursing at (386) 506-4032 or at abushy@mail.ucf.edu.

Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (IRB). Questions or concerns about research participants' rights may be directed to the Institutional Review Board Office, IRB Coordinator, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246. The telephone numbers are (407) 823-2901 and (407) 882-2276.

#### CONSENT

I have read the above information about photographing my artwork have been given an opportunity to ask questions. I consent to having photographs of my artwork taken and have been given a copy of this consent document for my own records.

Participant's Signature and Date	
Participant's Address	



## APPENDIX E INITIAL RECRUITMENT BROCHURE





A study of women who have had breast cancer and began to create art after that diagnosis is being conducted by a doctoral student in the College of Nursing at the University of Central Florida, Orlando, Florida. The information for the study will be obtained by the researcher conducting interviews that will be audio-taped. Each interview may take one to two hours. Only the researcher will have access to the tape recordings. The recordings and the transcribed information from the recordings will be destroyed after the analysis of the information is completed. There is no direct benefit for participating in the study nor is there a penalty for not participating. There is no financial compensation to participants for participating.

#### Women who:

• Have been diagnosed with breast cancer

@ Began to paint, sketch or draw after a diagnosis of breast cancer

Are 18 years of age or older
 Can read and speak English

#### Are invited to contact:

Laurie Stark, RN, MS, Doctoral Candidate
Phone: 407-488-5658 Email: lstark@mail.ucf.edu

Faculty Supervisor: Dr. Angeline Bushy, PhD, RN

Phone: 386-506-4032 Email: abushy@mail.ucf.edu.

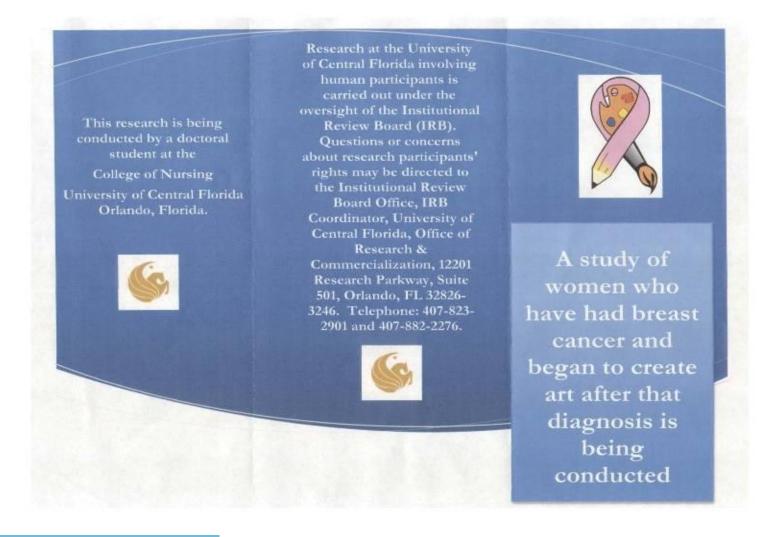
Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (IRB). Questions or concerns about research participants' rights may be directed to the Institutional Review Board Office, IRB Coordinator, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246. Telephone: 407-823-2901 and 407-882-2276.



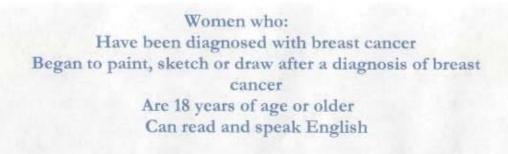


# APPENDIX F RECRUITMENT BROCHURE









Does this describe you or someone you know?



The information for the study will be obtained by the researcher conducting interviews that will be audiotaped. Each interview may take one to two hours. Only the researcher will have access to the tape recordings. The recordings and the transcribed information from the after the analysis of the There is no direct benefit for participating in the study nor is there a penalty for not participating. There is no financial compensation for

You are invited to contact: Laurie Stark, RN, MS, Doctoral Candidate Phone: 407-488-5658 Email: Istark@mail.ucf.edu

Faculty Supervisor: Dr. Angeline Bushy, PhD, RN Phone: 386-506-4032 Email: abushy@mail.ucf.edu.

## APPENDIX G INTERVIEW GUIDE



#### **Interview Guide**

## Warm up:

- Tell me about your favorite holiday
- What makes it so special for you?
- Are there certain foods served?
- With whom do you celebrate the holiday?

#### **Interview:**

- We are here so that you can tell me about your experience with breast cancer and creating art. While we are together I would like you to try to leave everything that may be bothering you or worrying you outside this room.
- Tell me how you came to know you wanted to paint after your diagnosis of breast cancer
- Tell me about your experience with breast cancer.
- Tell me about your art.
- Do you remember the first time you painted after your diagnosis? Tell me about that.

#### **Reflection:**

• A phrase or statement made by the study participant was be restated by the P.I. In an effort to obtain a deeper description or understanding of the experience.

### **Clarification:**

• The study participant was asked to clarify a statement or describe it further.

## **Request for examples:**

• The study participant was asked to provide an example of a particular portion of the dialogue.

## **Refocusing After a Digression:**

- The P.I. reformulated what the study participant had said up to the point that the conversation wandered.
- Portions of the interview restated by the P.I. were checked for accuracy with the study participant.



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