Assignment Of Meaning In The Male Breast Cancer Experience: A Phenomenological Study

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ASSIGNMENT OF MEANING
IN THE MALE BREAST CANCER EXPERIENCE:
A PHENOMENOLOGICAL STUDY

by

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This dissertation meets the standards for appearance, conforms to the style and format requirements of the Graduate School of the University of North Dakota, and is hereby approved.

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to my mother Ethel Mortvedt,
and to the memory of my biggest cheerleader,
my father, Reuben Mortvedt
ABSTRACT

The purpose of this phenomenological study was to gain an understanding of the lived experience of being a male diagnosed with breast cancer. With almost 200,000 cases of breast cancer diagnosed annually in the United States, a fact often overlooked is that approximately one percent of the newly diagnosed patients are male. Because of their small numbers, however, very little is known about how males are affected by a diagnosis of breast cancer. In order to provide holistic nursing care to affected men and their families, it is important that nurses have an understanding of the male experience with breast cancer.

The study aim was accomplished by conducting a semi-structured interview with men who had been diagnosed with breast cancer at least one year, but not more than five years prior to the interview. Interviews continued until data saturation was reached. Six men were included in the study.

This qualitative research involved phenomenology, allowing the researcher to collect data according to the views of the men themselves. The study was framed on the philosophy of Maurice Merleau-Ponty, a French philosopher who viewed the human body as the avenue through which one interacts with and adapts to the world. The study framework also included the Health Belief Model, which allowed investigation of male help-seeking behavior during the breast cancer experience.
Findings of the study included the emergence of the following ten major themes: 1) Breast cancer was something to take in stride – deal with it and get on with life; 2) Humor and the quest for normalcy helped with coping; 3) Breast cancer served as a wake-up call and brought with it a sense of vulnerability; 4) Body image was minimally affected; 5) Negative outcomes were challenges; 6) Positive outcomes were blessings; 7) Changes in time perception were subtle and may have been unrelated to the breast cancer experience; 8) Social and spiritual support was meaningful throughout the breast cancer experience; 9) Delay in seeking treatment was multi-factorial; and 10) Availability of more information would have contributed to increased autonomy.
CHAPTER 1

INTRODUCTION

Cancer Information

Cancer in the United States constitutes a major health concern, with approximately one in four deaths being attributed to cancer (Jemal et al., 2004). With almost 200,000 new cases of breast cancer expected to be diagnosed in the United States in 2007, breast cancer continues to be a major health concern (American Cancer Society, 2007). A fact often overlooked, however, is that approximately one percent of the patients with newly diagnosed breast cancer will be male (Jepson & Fentiman, 1998), and approximately 450 men die of the disease in the United States annually (American Cancer Society, 2007).

A relatively small amount of literature is available related to male breast cancer. Jepson and Fentiman (1998) believe that it may never be possible to learn as much about breast cancer in males as has been learned about the disease in females. This is indeed unfortunate, given the fact that research has shown that breast cancer in males displays a distinctly different physiological evolution and progression when compared to breast cancer in women (Muir, Kanthan, & Kanthan, 2003).

The male psychological response to being diagnosed with breast cancer may also be very different than the female response. The disease, which can be
devastating to both patients and families, may be complicated by the fact that men may feel isolated, disempowered, and less masculine due to their diagnosis with what they consider to be a female disease (Leonard, 2004). Since breast cancer may be experienced very differently in males, it is crucial that nurses gain an understanding of the male experience in order to provide optimal care for male breast cancer patients.

Statement of Significance

No matter what the patient’s circumstances may be, a breast cancer diagnosis tends to affect every aspect of a person’s life. Because they account for only one percent of breast cancer cases, very little is known about how males are affected by a diagnosis of breast cancer. Yet approximately two thousand men each year are diagnosed with breast cancer (American Cancer Society, 2007), considered by many to be a female disease (Leonard, 2004).

Gateley (1998) noted that the risk of male breast cancer increases exponentially with age. As the population in the United States ages, therefore, it may be anticipated that more and more men will be diagnosed with breast cancer. In order to provide holistic nursing care to these men and their families, it is important that nurses have an understanding of the male experience with a breast cancer diagnosis. Although there is a growing body of knowledge about the physiological effects of male breast cancer, very little information is available about how a diagnosis of breast cancer affects a man mentally, emotionally, or spiritually.
Study Aim

The purpose of this study was to explore the lived experience of males who have been diagnosed with breast cancer. The focus of the research was from the time that symptoms were first noticed until one year post-diagnosis, as completion of treatment typically occurs during the several months after diagnosis. It is during that time that patients face significant adjustment issues (Friedewald & Buzdar, 1997). It is hoped that gaining an understanding of this experience will assist nurses in providing optimal care for male breast cancer patients.

The study explored the following questions: 1) What meaning may be found in the lived experience of being diagnosed with male breast cancer? 2) How does the diagnosis of breast cancer affect one's life? 3) What effect does support of family/friends have on the experience? 4) What role, if any, does the spiritual/belief system play? 5) What factors influence decisions to seek treatment or cause delay in seeking treatment?

The study aim was accomplished by conducting a semi-structured interview with each study participant. Demographic information related to age, marital status, personal health history, family history of breast cancer, socioeconomic status, health insurance coverage, religion/spiritual belief system, activity level, disease status, support system, ethnic group, education, and employment history was also reviewed. Each of the demographic questions was asked to provide a broad picture of the participant's background, to add direction.
to appropriate areas of the interview, and/or to evaluate how the individual's experience compared with information found in literature.

This qualitative study used a phenomenological approach that allowed the investigator to collect data according to the views of the men themselves. The information was shared by the participants during a semi-structured interview, thus contributing to the development of an understanding of the experience of being diagnosed with breast cancer.

Philosophical Underpinnings

Maurice Merleau-Ponty's philosophy was used to explore the experience of being diagnosed with male breast cancer. A French philosopher, Merleau-Ponty viewed the human body as both subject and object. According to Merleau-Ponty's view of corporeality, the body cannot be viewed as separate from the spirit. This embodiment, as described by Benner (1994), is the way that one comes to interact with and adapt to one's world, through the physical body itself. It is the body that is instrumental in selecting ways to react, often acting separately from the conscious mind. A phenomenological approach based on Merleau-Ponty's philosophy was used in the hope of bringing understanding of the male perception of this disease which affects the body so significantly.

In addition to Merleau-Ponty's belief that one's body is the avenue through which one experiences the world, his views related to habituality, temporality, and expressivity helped to guide the study. Habituality, the tendency of the body to seek balance through establishment of routines, was explored in relationship to how daily life changed for the participant as a result of the breast cancer.
diagnosis. Temporality, the tendency to experience time by being consistently drawn toward the future, was explored by asking about any changes in the way that the participant views his future. Connections between thought and interaction with the world, through verbalization or body language, are known as expressivity (Merleau-Ponty, 1945). Expressivity was explored by asking the participant about any changes in interactions or relationships as a result of the diagnosis. Using Merleau-Ponty’s thoughts on corporeality, habituality, temporality, and expressivity was helpful in gaining insight into changes in the participant’s life during the period surrounding the breast cancer diagnosis.

In order to understand the male response to breast cancer, it is also important to examine male help-seeking behavior in general. A model that is helpful in gaining perspective related to help-seeking is the Health Belief Model, which serves as a theoretical framework for understanding or predicting help-seeking behaviors (Pierce, Chadiha, Vargas, & Mosley, 2003). The model, developed in the 1950’s, emerged as a way to gain understanding about why people hesitated to participate in screening and immunization programs. It is based on the assumption that understanding a person’s help-seeking motivation is an essential first step in exploring the patient’s behavior pattern (Rosenstock, 1960).

Since its development over 50 years ago, the Health Belief Model has been used extensively, and it has been applied in the study of many diseases (Turpin et al., 2004). During its continuing evolution, it has drawn the greatest amount of empirical support of any model related to health beliefs (Heiby,
Lukens, & Frank, 2005). Widely used in studies related to both disease-prevention and treatment compliance, the Health Belief Model is considered to be a value-expectancy theory. In value-expectancy theories, behavior is viewed in light of the subjective value of an outcome, along with the individual's expectation that a particular action will result in the desired outcome (Vincke & Bolton, 2002). Also considered to be a staged theory, it is believed that each step in the process of making health-related decisions is dependent on the resolution of the individual's previous decision or perception (Hollister & Anema, 2004).

Application of the Health Belief Model helps to provide insight into the individual's decision-making process, which is greatly influenced by personal values and beliefs (Doukas, Localio, & Li, 2004). Based on the work of psychosocial theorists, the model proposes that behavior is driven by an individual's cues to action, along with perceptions about susceptibility, severity, benefits, and barriers (Poss, 2001). It is thought that the course of action ultimately chosen by the individual is reflected in the Health Belief Model as a cost/benefits analysis, where each health-related behavior is weighed in terms of its perceived benefits and barriers (Lollis, Antoni, Johnson, Chitwood, & Griffin, 1995). A specific health behavior, therefore, will have little probability of being performed if the costs are perceived as high, the benefits are perceived as low, or one's attitude toward the action in general is negative (Dale, Sartor, Davis, & Bennett, 1999).

Although it has been commonly accepted and widely used in research with many diseases, there has also been criticism of the Health Belief Model.
Some researchers believe that the Health Belief Model provides limited opportunity for addressing psychosocial factors such as social support, economic factors, and attitudes toward illness (Pierce et al., 2003). The model is also criticized for being a poor predictor of treatment compliance in chronic illness (Weinstein, 1993), as well as being deficient in accommodating for cultural beliefs (Lin, Simoni, & Zemon, 2005).

In an effort to increase the effectiveness of the model's application, it has been suggested that other models or theories, as appropriate to the subject being researched, be used in conjunction with the Health Belief Model. For example, one concept that has been used in conjunction with the Health Belief Model in recent years is self-efficacy, a concept found in social cognitive theory (Wulfert & Wan, 1995). Recent research has suggested that studying the concept of self-efficacy as an addition to the Health Belief Model will help to improve the model's research power (Vincke & Bolton, 2002). Self-efficacy, as explained by Bandura (1999), is the individual's belief that he or she has the ability to perform the action needed to arrive at the desired outcome. High self-efficacy can help to overcome barriers that prevent desired health behaviors. Without the addition of the concept of self-efficacy, the Health Behavior Model is believed by some to fall short of accurately accounting for variances in behavior (Park, Chang, & Chung, 2005).

The Health Belief Model, used alone, has often resulted in conflicting outcomes (Wulfert & Wan, 1995; Stiles & Kaplan, 2004). There is disagreement as to the reasons for the conflicting results. It has been suggested that cross-
sectional studies may yield the strongest results when applying the Health Belief Model, while longitudinal studies have been shown to exhibit weaker results (Hollister & Anema, 2004). Norman and Brain (2005), however, believe that cross-sectional studies using the Health Belief Model do not provide an adequate testing condition, noting that correlation outcomes are likely to be inflated when health beliefs are measured at the same time as health behavior. They suggest that prospective designs offer the best opportunities for application of the Health Belief Model. Clarke, Lovegrove, Williams, and Machperson (2000) note that study results may also be affected by the fact that unrealistic optimism will often affect an individual's perceptions related to illness, a factor not well-covered by the Health Belief Model.

The following diagram may be helpful in clarifying the Health Belief Model:

Figure 1. The Health Belief Model
When applying the Health Belief Model to a man who finds a lump in his breast (his cue to action), the man may delay seeking medical attention due to his perceptions of the situation at hand. If he does not believe that he has breasts, and therefore cannot get breast cancer (perceived susceptibility), he will not be motivated to have the lump examined by a physician. Since the man does not believe that he can get breast cancer, the lump is thought to be something minor, so he may decide to wait to see if it will go away by itself (perceived severity). Thinking that the lump must be a minor issue, it may not be viewed as a productive use of his time to visit a doctor unless he finds that the lump is not resolving on its own (perceived benefits). There may also be issues that keep him from wanting to have the lump checked out such as peer pressure, lack of time, or embarrassment (perceived barriers). According to an article in the National Post (Suhanic, 2005), embarrassment is often so significant that it will prevent a man from visiting a physician even though symptoms of the illness have advanced. Gaining insight into what motivates men to seek treatment when breast cancer symptoms are discovered will contribute to increased understanding of the lived experience of male breast cancer.

Assumptions

It was assumed that

- the males identified as potential candidates for the study would be willing to participate in the study
- study participants would be able to recall feelings and events that occurred during the period surrounding the breast cancer diagnosis
participants would be willing to share their perceptions of the breast cancer experience openly and honestly.

Definitions

Corporeality – the way that one comes to interact with and adapt to one’s world, through the physical body itself (Benner, 1994)

Expressivity – connections between thought and interaction with the world, through verbalization or body language (Merleau-Ponty, 1945)

Habituality – the tendency of the body to seek balance through establishment of routines (Merleau-Ponty, 1945)

Physiological – related to body function (Thomas, 1997).

Psychological – related to the processes of the mind (Thomas, 1997).

Social Support – having a sense of belonging, or feeling valued and accepted for oneself (Harkreader & Hogan, 2004)

Spirituality – an energy force within the human core that seeks to return to and commune with the God source from which it came (Neuman & Fawcett, 2002).

Temporality – the tendency to experience time by being consistently drawn toward the future (Merleau-Ponty, 1945)

Summary

Approximately one percent of the patients with newly diagnosed breast cancer in the United States are male (Jepson & Fentiman, 1998), and about 450 men will die of the disease annually (American Cancer Society, 2007). A relatively small amount of literature is available related to breast cancer in males,
even though research has shown that breast cancer in males displays a distinctly different physiological evolution and progression, when compared to breast cancer in women (Muir et al., 2003). The male psychological response to being diagnosed with breast cancer may also be very different than the female response, as men may feel isolated, disempowered, and less masculine due to their diagnosis with what they consider to be a female disease (Leonard, 2004).

It is crucial that nurses gain an understanding of the male experience of being diagnosed with breast cancer in order to provide optimal care for male breast cancer patients. This study provides a means for gaining insight into the male breast cancer experience.

The following chapters will include a review of literature (Chapter 2), a methodology section (Chapter 3), an analysis of results/findings (Chapter 4), and a discussion section including summary, conclusions, and recommendations (Chapter 5).
CHAPTER 2
LITERATURE REVIEW

The vast majority of literature addresses breast cancer in females. There is a very limited, but growing, amount of research-based literature related to the subject of male breast cancer, but more research is needed (Giordano, 2003). This literature review contains information related to the physiological, psychological, and spiritual aspects of male breast cancer, as well as the role of social support.

Breast Cancer Facts

With almost 200,000 new cases diagnosed in the United States yearly, breast cancer continues to be a major health concern (American Cancer Society, 2007). Although the percentage of males diagnosed with breast cancer has remained around one percent of all new cases for the past several decades, authorities disagree as to whether the percentage is truly remaining stable or whether it is slowly climbing (Giordano, Cohen, Buzdar, Perkins, & Hortobagyi, 2004; Giordano, Buzdar, Aman, & Hortobagyi, 2002; Shapiro, 1998). Changes in diagnostic methods and treatment regimens through the years have made interpretation of statistics more difficult (Atalay, Kanlioz, & Altinok, 2003). In addition, there is variability when looking at men of different age groups. According to Perkins and Middleton (2003), for example, there has been a
substantial increase in breast cancer rates in males under the age of forty, a trend reflected globally.

Comparison of Male and Female Disease

Even though the number of male patients diagnosed with breast cancer is small in relation to the female population, further study of male breast cancer is imperative. Despite the tremendous advances that have been made in the medical field in general, there has been little improvement in the outcomes related to male breast cancer in the last twenty-five years (O'Malley, Prehn, Shema, & Glaser, 2002).

Recent years have also seen phenomenal growth in the effort to increase public awareness about breast cancer in women. Public awareness and increased knowledge about breast cancer, along with screening programs, have translated into earlier detection of breast cancer among women, thus improving their outcomes. For the most part, men have regrettably been left behind in the quest to increase public awareness (Giordano et al., 2004).

If male breast cancer is truly a distinct disease physiologically, therapeutic management strategies should also be based on the male disease process, rather than the female disease experience. It has even been proposed that the study of male breast cancer, which progresses without complicating factors such as menstruation and childbearing, may be an ideal way to gain a better understanding of breast cancer in females as well (Newman, 1997).

When compared to female breast cancer, some researchers believe that males do not fare as well as females in the outcomes of their breast cancer
(Ravandi-Kashani & Hayes, 1998). However, when matched with women related to age, tumor size, stage, and nodal status, prognosis is thought by some investigators to be similar for both male and female patients (Jepson & Fentiman, 1998). On the other hand, El-Tamer et al. (2004) studied 53 equally-matched patients of each gender, finding that males had “significantly better disease-specific survival” than females (p. 1081). A distinct difference though has been identified among both genders when considering expected outcomes in the light of racial/ethnic differences.

Ethnic Considerations

African Americans, as a group, have the highest overall incidence of cancer compared with any other racial or ethnic group in the United States, along with the worst morbidity and mortality rates (Hamilton & Sandelowski, 2004). In females with breast cancer, it has been found that black women have lower five-year survival rates than white women. The survival rates of Hispanic women are similar to the white population, while Asians/Pacific Islanders have been found to have the longest survival rates (O'Malley et al., 2002). Ashkenazi Jews are considered to be at significantly higher risk of male breast cancer than men of other races (Meguerditchian et al., 2002).

Review of statistical evidence related to males reveals that black men diagnosed with breast cancer have a 57% five-year survival rate compared with 66% for white men and 75% for other ethnic groups. It is believed that the better survival rates for people of other races, such as Asians/Pacific Islanders, suggest a protective influence unrelated to gender. Speculation is that the increased
survival time is related to genetics, body size, or lifestyle factors such as nutrition (O’Malley et al., 2002).

Physiological Considerations

A relatively small amount of literature is available related to the physiological effects of male breast cancer. O’Malley et al. (2002) found that most of the information related to breast cancer in males has been based on studies conducted with female patients. On the other hand, studies with male patients are typically based on small populations and reflect the experiences of a single institution (O’Malley et al., 2002).

Some breast cancer investigators believe that knowledge about breast cancer in males will always be limited when compared to what has been learned about the disease in females (Jepson & Fentiman, 1998). Because of the research difficulty in the field of male breast cancer, the clinical management of males continues to be guided by research on females (O’Malley et al., 2002). This is indeed unfortunate, given the fact that research has shown that breast cancer in males displays a distinctly different evolution and progression, when compared to breast cancer in women (Muir et al., 2003). Breast cancer’s distinctive characteristics in men include a high percentage of positive hormone receptors, diagnosis at a higher grade, and a high percentage of ductal carcinoma (Gateley, 1998). Lobular carcinoma in males is extremely rare, since the male breast consists of mostly ductal tissue (Loerzel & Dow, 2004). Some investigators believe that lobular cancer in men may be an indicator of other
pathological processes, as development of breast lobules in the male patient is atypical (Muir et al., 2003).

In order to gain an understanding of the experience of being diagnosed with male breast cancer, one must first examine physiological factors related to the disease. Important physiological issues to be addressed in this section include risk factors, diagnosis, treatment, and prognostic factors.

**Risk Factors**

Age, testicular abnormalities, family history, race, and environmental factors are some of the major factors that may increase a man's risk of breast cancer. While men of any age may be affected, the risk for breast cancer increases exponentially with aging. According to Gateley (1998), the incidence of male breast cancer at age 35 is 0.1 per 100,000, but it rises to 9 per 100,000 by the age of 90, with no mid-life change in slope as may be seen in women. Breast cancer may be diagnosed in men at any point in life and has been reported in males from the age of five to well into the nineties. The median age at which men are diagnosed with breast cancer is 68, compared with 63 years of age in women (Giordano et al., 2002).

It should also be noted that breast tissue, which contains prostate specific antigen, may contain tumors which have metastasized from prostate cancer, rather than being a primary breast cancer. Some forms of treatment for prostate cancer have also been found to increase the risks of breast cancer in males (Thellenberg, Malmer, Tavelin, & Gronberg, 2003). Although both cancers are very responsive to hormones, cases of men having both a primary breast cancer
and a primary prostate cancer are extremely rare (Leibowitz et al., 2003). Auvinen, Curtis, and Ron (2002) state that no evidence has been found to link breast and prostate cancer, even though both may be hormone-dependent.

Any factor that increases estrogen places a man at higher risk for breast cancer. Because damage to the testicles, either by trauma or congenital syndrome, will cause an estrogen/androgen imbalance, any testicular abnormality constitutes a significant risk factor. Some testicular maladies that may contribute to an estrogen imbalance include undescended testicles, congenital inguinal hernia, orchiectomy, and traumatic injury to the testicles such as may happen in a bicycle or motor vehicle accident (Giordano et al., 2002; Omari-Alaoui et al., 2002).

Liver disease, such as cirrhosis, and obesity may also contribute to an increased estrogen level, as well as hormone replacement therapy undertaken by individuals who have had prostate cancer or a gender change operation. Alcoholism alone may lead to gynecomastia (Gateley, 1998), but it is not thought to increase the risk of breast cancer unless it is in the context of alcohol-related cirrhosis (Meguerditchian, Falardeau, & Martin, 2002). When considering the incidence of alcohol-related cirrhosis and obesity in our population today, along with physical inactivity which is also an identified risk factor (American Cancer Society, 2007), it may be anticipated that the incidence of male breast cancer will continue to be problematic.

A family history of breast cancer is another risk factor. Men who have a first-degree male or female relative with breast cancer are at slightly higher risk,
although their overall risk is still low (Giordano, 2003). It should also be noted that a man with breast cancer creates a family history for both his male and female family members. Gene mutations such as BRCA2, carried by ten to twenty percent of male breast cancer patients, may be passed along to male and female children, thus placing them at higher risk for breast and ovarian cancer (Giordano, 2003).

Ethnicity has also been found to be a factor. In the United States, black men are at higher risk for breast cancer than white or Asian men (Sasco & Fontaniere, 1991). It is unclear whether the higher risk among African Americans is related solely to genetics, as lifestyle differences must also be considered. For example, it has been found that the percentage of males diagnosed with breast cancer is higher among people who are socioeconomically disadvantaged (Peate, 2001). Research, however, has also revealed that, in sub-Saharan Africa, up to thirteen percent of all breast cancer is found in males (Meguerditchian et al., 2002).

There are also many environmental factors, such as working in excess heat or being exposed to estrogen, which may contribute to a higher risk of breast cancer. Prolonged exposure to excess heat is associated with a higher risk of breast cancer, thus increasing the frequency of male breast cancer in tropical climates (Yildirim & Berberoglu, 1998). Any work environment that exposes a man to high degrees of heat, such as may occur with furnace and steel workers, can suppress testicular activity, thus upsetting the androgen/estrogen balance. Men may also be exposed to external sources of
estrogen, such as may be encountered when working with cosmetic products containing estrogen creams. Butchers may be exposed to growth hormones that use estrogen in animals. Those who are exposed to radiation and electricity in their work may also be at increased risk (Jepson & Fentiman, 1998; Meguerditchian et al., 2002).

Klinefelter’s syndrome is thought to place a man at 20 times higher risk for breast cancer than the general male population (Meguerditchian et al., 2002). Klinefelter’s syndrome is a congenital condition in which men have one or more extra X chromosomes. Affecting 0.1% of men, this syndrome causes a decrease in testicular size, thus reducing sperm cells and androgen levels. In the presence of the decreased androgen levels, estrogen levels are increased, leading to gynecomastia and infertility (American Cancer Society, 2007).

Although it may be associated with Klinefelter’s syndrome, gynecomastia itself does not place a man at higher risk of breast cancer as was once commonly believed. Other benign breast conditions, however, such as recurrent cysts, breast trauma, and nipple discharge may indicate a greater propensity for breast cancer (Giordano et al., 2002).

**Diagnosis**

Diagnostic tests for males are similar to those used for females. Once signs of a possible cancer have been discovered, the male patient may have a mammogram, ultrasound, and biopsy, just as would occur in the female patient. A difference that should be noted is that men are frequently diagnosed at a later stage than females, often meaning that the cancer is more advanced before it is
detected (Shapiro, 1998). Even though a breast tumor in a male may be small at the time of diagnosis, it is much more likely to have metastasized prior to diagnosis due to the small amount of breast tissue present in males (Mudlin, 2002). Because there is not a concerted effort to make men aware of early signs of breast cancer, and because there are no screening recommendations in place, men frequently ignore signs of the disease. Often a breast mass will have been noticeable for several months before treatment is sought (Shapiro, 1998; Gateley, 1998).

**Treatment**

The typical surgical treatment for breast cancer in males is a modified radical mastectomy (Gateley, 1998). Because the tumor mass usually starts centrally, involving the nipple complex early in its course, lumpectomy is rarely performed (Peate, 2001). There is also little cosmetic benefit from attempting to perform a partial mastectomy or lumpectomy.

Although every type of breast cancer has been identified in men, the vast majority of male patients are diagnosed with invasive ductal carcinoma (Ravandi-Kashani & Hayes, 1998). Because of the invasive status of the cancer, the axillary lymph nodes must be sampled. This serves the dual purpose of revealing the state of the lymph nodes, which is necessary for staging, as well as removing lymph nodes which have been affected by the disease (Gateley, 1998).

Sentinel lymph node mapping, in which the first node in the lymph chain is removed and tested, has recently become standard practice in many cancer centers in the United States. If the first node proves to be cancer-free, the
remaining lymph nodes are left intact, thus decreasing the chance for lymphedema and promoting more rapid healing. If it is found that cancer has spread to the sentinel node, an axillary dissection to remove the remaining lymph nodes will be performed. Sentinel lymph node mapping, based on its success with female patients, is starting to gain popularity in the treatment of male patients (Port, Fey, Cody, & Borgen, 2001).

Other treatment options include chemotherapy, radiation, and hormone therapy. Unlike female patients, it is approximated that over three-fourths of men have tumors with positive estrogen or progesterone receptors. Giordano (2003) estimates that greater than 90 percent of male breast cancer patients have a positive estrogen receptor status, indicating that male breast cancer is more likely to be stimulated to grow when exposed to estrogen. This increases treatment options with hormone therapy, as a patient with positive hormone receptors may be effectively treated with hormone-blocking medication (American Cancer Society, 2007). Hormone-blocking medication would be of no effect in a person with a negative hormone receptor status. Some investigators believe that the higher percentage of positive hormone receptors in males, however, may not translate into a better prognosis, as it does in women (Muir et al., 2003). On the other hand, Moore et al. (1998) found that positive estrogen and progesterone receptors did lead to a more positive prognosis. Even though male breast cancer tumors may be quite responsive to hormonal therapy, treatment with hormone blockers may lead to significant side effects. Approximately two-thirds of the men who take them experience side effects such
as hot flashes, decreased libido, mood changes, insomnia, and impotence (Meguerditchian et al., 2002).

Prognostic Factors

Prognostic indicators are based on the same factors in men and women. Tumor size, stage, and the number of histologically positive lymph nodes are of prime importance in predicting outcomes (Guinee et al., 1993). Some investigators do contend that male breast cancer survival rates remain less favorable than survival rates of their female counterparts (Levi, Lucchini, & LaVecchia, 2002), but this is most probably based on the fact that many studies look at overall survival rates, rather than comparing patients who have similar prognostic indicators. The view that males do not fare as well as females in the outcome of their breast cancer may also be based on the fact that men often present for treatment after their cancer has already reached an advanced stage (Muir et al., 2003).

It is important to consider all of the variables when comparing prognostic issues related to male and female breast cancer. Overall, it appears that, when matched with women related to age, tumor size, stage, and nodal status, prognosis appears to be approximately the same for male and female patients (Jepson & Fentiman, 1998).

Psychological Considerations

Although there is a limited amount of physiologically-based research related to breast cancer in males, there is an even greater dearth of research related to psychological impact. Important psychological issues to be addressed
in this section include self-esteem/body image, and male help-seeking behavior/masculinity.

**Self-Esteem/Body Image**

Much of the research among female breast cancer patients focuses on issues of self-esteem and altered body image, as many women believe that their breasts are symbolic of their femininity (Oktay, 1998). This contributes to the belief that breast cancer is a female disease (Donovan & Flynn, 2007). The myth that breast cancer is a female disease has been further proliferated by the fact that men have been thought to have little sexual or emotive association with their breasts (France et al., 2000). Many men have stated that they were unaware that men could ever get breast cancer (Maher, 2003). Indeed, some men have even stated they never thought that they had breasts until they were diagnosed with breast cancer (Kazanjian, 1995).

Because breast cancer is typically considered to be a female disease, the quest for learning about the male psychological response is important. The disease, which can be devastating to both patients and families (Peate, 2001), may be complicated by the fact that men may feel isolated, disempowered, and less masculine due to their diagnosis with what they consider to be a female disease (Leonard, 2004). According to a recent article in the National Post (Suhanic, 2005), embarrassment is often so significant that it will prevent a man from visiting a physician even though symptoms of the illness have advanced.

Treatment for breast cancer will also result in a change in the male's body. It must be remembered that the male's body image will be based on his own
perception, and will ultimately have an effect on his personal confidence and self-esteem (Timpson, 1999). While it may not be assumed that all men attach symbolic meaning to their breasts, a disruption in the symmetry of the chest due to scarring may be devastating to a male's body image (Donovan & Flynn, 2007). For some men, the nipples are highly sensitive. According to Donovan and Flynn (2007), a nipple may be “considered to be as much a sexual organ in its own right as the male reproductive genitalia” and its loss “could have profound emotional and sexual consequences” (p. 465). Reaction to changes in the body will, of course, be different for each person and will depend on the individual's own values and perceptions (Norris & Spelic, 2002). The effect of the change in body image, however, should be thoroughly assessed and should not be underestimated.

**Male Help-Seeking Behavior/Masculinity**

The Health Belief Model will be helpful in gaining insight related to male help-seeking behavior. The model, which was developed in the 1950's, emerged as a way to gain understanding about why people hesitated to participate in screening and immunization programs (Rosenstock, 1960). Based on the work of psychosocial theorists, the Health Belief Model proposes that behavior is driven by an individual's cues to action, along with perceptions about susceptibility, severity, benefits, and barriers (Poss, 2001).

It is of interest that there is no literature exploring male breast cancer within the framework of the Health Belief Model. It seems clear that there is a great need for further investigation of male help-seeking behavior, especially as it
relates to breast cancer in men. Application of the Health Belief Model within nursing research with male breast cancer patients may help to shed light on what factors influence help-seeking early in the disease process. Until more understanding is gained in this area, it will be difficult to appropriately address the factors that may cause delay in seeking treatment.

Among men in the United States, the issue of masculinity may be a very common issue with which a man must deal when diagnosed with breast cancer. Perceived risk to masculinity has been identified as an especially common cause for Caucasian middle class men to delay seeking treatment for an illness (Galdas, Cheater, & Marshall, 2005). According to Thomas (2004), many men have been socialized to believe that vulnerability is a sign of weakness. Young boys are therefore taught to be silent about their emotions, thus indicating control over themselves (Thomas, 2004). Since illness is in direct conflict with the Western myth of masculinity, it may be very difficult for men to accept illness and its associated fears, needs, and perceived loss of control (Moynihan, 1998).

The Western view of masculinity, associated with strength and self-reliance, may cause men to have a greater tendency than women to conceal their vulnerability, thus decreasing their willingness to seek help when first becoming aware of signs of illness (Davies et al., 2000). This may help to explain why an enlarging breast mass could be ignored for several months before treatment is sought (Shapiro, 1998; Gateley, 1998). In the light of the Health Belief Model, a barrier as significant as a perceived threat to one's masculinity may easily contribute to delay in seeking health care.
Interestingly, it has even been reported that men with a family history of breast cancer have a tendency to drop out of protocols for genetic testing in which they had been enrolled, thus exhibiting avoidance rather than being willing to learn about their own susceptibility (McAllister, Evans, Ormiston, & Daly, 1998). A similar situation has been identified in testicular cancer research. According to Brodsky (1999), testicular cancer patients may delay treatment due to denial, feelings of threat to their self-esteem, or thought that their symptoms may be minor.

Davies and his colleagues (2000) also found that college-aged men were fearful of seeking help unless they believed they had sufficient reason. They believed that their pain should be extreme before seeking medical treatment, thus avoiding the possibility of being judged in a negative light by their peers. Men have also cited lack of time, financial concerns, and family or work responsibilities as reasons for avoiding medical treatment when it is needed (Davies et al., 2000; Leydon, Bynoe-Sutherland, & Coleman, 2003).

Plowden (2000), in a study of the health-seeking behavior of African-American men, found that fatalism was a major factor in delaying medical treatment. For many African-American men, seeking health care is done only after all other attempts to relieve the symptoms of illness have failed (Plowden & Miller, 2000).

Admission of fear or concern may be difficult for men who are raised to avoid communication of such issues. Avoiding discussions with others about the illness or giving the impression that things are going fine may further isolate the
male who is dealing with illness at a time when social support is of great
importance (Leydon et al., 2003). It is not surprising, therefore, that males have
been found to adjust to cancer-related stress in a much less positive way than
females (Fife, Kennedy, & Robinson, 1994).

A study of men in Finland diagnosed with various types of cancer found
that men considered their cancer experience to be only temporary. Even though
they experienced feelings of helplessness and struggles with coping at the times
of diagnosis and treatment, they were able to view the experience as a transition
time that would be only short-term. The men in this study were able to express
their feelings to others, thus allowing their overall experience to be viewed more
positively. The investigators acknowledged that it was men who were
comfortable sharing their feelings that participated in the study, while those who
declined to participate in the study may have had an entirely different outlook on
the cancer experience (Vaartio, Kiviniemi, & Suominen, 2003).

In a study of men who were dealing with prostate cancer, it was found that
a large percentage of the patients were not willing to discuss their illness even
with other prostate cancer patients in a support group setting (McGovern,
Heyman, & Resnick, 2002). On the other hand, a survey of men who sought
reproductive health services in a California clinic was conducted. Approximately
half of the participants said they had come to the clinic only after discussing their
decision to seek help with at least one other person (Raine, Marcell, Rocca, &
As a disease, cancer has also been found to evoke negative feelings in those who may be closest to the cancer patient (Flanagan & Holmes, 2000). A breast cancer diagnosis may strain relationships, decreasing the possibility of adequate emotional support when it is most needed (Oktay, 1998). Considering the importance of the social context in seeking help for preventive or minor issues, its value in overcoming barriers to help-seeking in the context of major illness, such as breast cancer, should not be underestimated.

Spirituality

A person with an illness such as breast cancer is forced to face not only the diagnosis of breast cancer, but also to make significant decisions within a short period of time. These decisions include what type of treatment to obtain, how to tell family and friends, and how to try to return to a sense of normalcy. In addition to the urgent decisions that need to be made, the newly diagnosed patient with breast cancer must also confront spiritual challenges such as searching for meaning and seeking a sense of resolution (O'Neill & Kenny, 1998).

When facing such a daunting challenge, a breast cancer patient is often expected to quickly learn to cope with illness, treatment, and recovery. Wonghongkul, Moore, Musil, Schneider, and Deimling (2000) found that ability to cope is closely related to survival and quality of life. Strengthening the spiritual aspect of self will help the patient to build the coping mechanisms needed to deal with a diagnosis of breast cancer (Neuman & Fawcett, 2002).
Coping mechanisms, along with spirituality issues, will be a significant determinant of how the newly diagnosed breast cancer patient will function. Research related to spirituality in the light of major illness has shown that a person's own spirituality is the most powerful resource for coping with health-related issues (Narayanasamy, 2003).

Baldree, Murphy, and Powers (1982) reported that formal religion, not surprisingly, was an important source of support and strength for many patients who were dealing with a major illness. They also found, however, that hope, prayer, and trust in God were prominent methods of coping among the chronically ill.

Although there has been a significant amount of research demonstrating that spirituality plays a major role in coping with an illness, there have been fewer studies that demonstrate what may help to enhance a person's sense of spirituality. One factor that has been studied, however, is prayer.

Prayer, defined by Shelly and Fish (1995) as an intimate conversation between a person and God, has long been identified as a source of strength by patients and caregivers alike. A study conducted by Ai, Dunkle, Peterson, and Bolling (1998) demonstrated that private prayer among patients resulted in decreased depression and general distress one year after major surgery. This was found to be true of patients who stated that they prayed about their postoperative problems. Interestingly, most patients identified themselves as people who prayed frequently.
Prayer has also been identified as an important source of strength that should be shared with breast cancer patients by their caregivers, nurses in particular (Taylor, 2003). Taylor found that incorporating prayer into the caregiving experience helped to sustain coping and to bring comfort to patients at their time of greatest need.

Kantor and Houldin (1999) also found, in their study of the well-being of breast cancer patients, that nurses could offer much more in the line of psychosocial and spiritual care to patients. For a nurse who is serving as a patient advocate, it is necessary to provide all the resources possible to assist the patient to cope with a cancer diagnosis. This includes not only physical, but also psychosocial and spiritual resources. Kantor and Houldin believe that nurses should use every resource available to assist their patients to cope, including support groups, church and spiritual groups, and prayer.

Winslow and Winslow (2003) found in their research that prayer is an intervention with patients that is necessary to help to meet their spiritual and coping needs. Although they voice understanding that praying with a patient may present an ethical dilemma, they believe that the opportunity of providing someone with such a source of strength should not be neglected.

A study conducted by Theis, Diordi, Coeling, Nalepka, and Miller (2003) revealed that spirituality is important to caregivers and patients alike. They found that coping, in a spiritual sense, was enhanced by the patients and caregivers' participation in some type of formal religion and by the social support offered in the practice of their religion. The researchers found that attempting to meet the
spiritual needs of even the homebound (who were no longer able to attend formal church services) was helped by encouraging whatever participation was possible for the client. Some found great strength in watching a church service on television, reading the Bible, receiving communion, or spending time in intercessory prayer.

Shelly and Fish (1995) have researched the effects of prayer with patients for many years. Their simple definition of prayer as an intimate conversation between a person and God does not preclude nursing intervention in the area of prayer. It is their belief that whatever a nurse is able to do to enhance a person's relationship with God, thus contributing to coping skills, it falls within that nurse's practice.

A qualitative study conducted by Taylor and Outlaw (2002) explored the way that cancer patients utilized prayer. Patients in this study revealed that they found prayer to be a strong coping mechanism in their fight against cancer. The patients acknowledged that they used prayer to ease the distress caused by cancer in the physical, spiritual, and emotional realms.

Treloar (2000) agrees that spirituality is an important aspect of health care. She believes that nurses, especially nurse practitioners, are in an ideal situation to assess the spiritual needs of their patients. Treloar also thinks that spirituality should be a natural part of the healing arts, integrated into health care practice on a routine basis. Addressing the spiritual needs of the patient may be done in many different ways, from talking directly with the patient about spiritual
issues to providing opportunity for patients to practice their religion freely within the health care setting.

Social Support

The social context is another consideration in the breast cancer patient's experience. Social support has been found to be an important factor in a man's decision to seek help (Plowden, 2000; Raine et al., 2003). Ptacek, Pierce, and Ptacek (2002) learned that the support of friends may be less important as a man ages, as older men tend to become more dependent on the support of a spouse. They also discovered that perceived support was related to coping ability in men who were dealing with prostate cancer, and suggested that interventions aimed at strengthening support may lead to coping benefits for the patient.

Peleg-Oren and Sherer (2001) found that the spouses of cancer patients experienced as much psychological distress as the patient, as well as the same amount of difficulty with social adjustment. A breast cancer diagnosis, therefore, may negatively affect social relationships, jeopardizing emotional support at a time when it is most needed (Oktay, 1998).

Support of family is an important part of the cancer patient's journey. Families are defined in literature as a unique social group with generational ties, permanence, a concern for the total person, and a nurturing form of functioning (Leske, 1998). During times of serious illness, family members may tend to minimize their own needs, making them increasingly vulnerable to physical and psychological disorders (Walsh & Schmidt, 2003).
Finlay (2003) discussed vulnerability of family members who were facing the death of a loved one. Finlay advised that the story of each family member should be heard, thus bringing to life the struggle that people are experiencing (Kirkpatrick, Ford, & Castelloe, 1997). Perceived lack of interest in family members, on the other hand, may leave them feeling isolated, powerless, and angry. This may lead to the possibility of being labeled as difficult or noncompliant, resulting in further isolation. (Durham, 1998). According to Heiney (1993), being allowed to tell their stories may also help families to find meaning and purpose in their experiences. Talking about their experiences should be viewed as a therapeutic technique (Leske, 1998). Donnelly (2003) suggests that the story of the patient and the family bears the feelings and experiences, as well as the objective evidence of illness, that must be identified in order to provide optimal quality of care.

Clark (1981) found that social support was the single most important factor in a cancer patient’s adjustment. Loerzel and Dow (2004), however, caution that health care providers must be careful when considering the social support needs of male breast cancer patients. They believe that social support interventions, such as recommendations for support groups, must be made based on the individual characteristics of the patient, since many men may be embarrassed to discuss their experiences openly.

Summary

Although the body of knowledge specific to the area of male breast cancer is limited, the amount of literature available is slowly increasing. While the
majority of the available literature is physiologically-based, it is hopeful that there will be increased research interest related to the social and psychological issues related to male breast cancer.

It seems clear that there is a great need for further investigation of male help-seeking behavior, increased awareness of signs of illness, and greater efforts to educate the public, especially as it relates to breast cancer in men. Any effort will be futile, however, unless the end result is behavioral change in help-seeking behavior (Currie & Wiesenber, 2003). Gaining a deeper understanding of the physiological and psychosocial factors involved in male breast cancer, as well as the barriers that cause delay in seeking health care, will help to optimize the health care offered to male breast cancer patients. Exploring factors such as spiritual and social support that are important to help-seeking, as well as to coping and recovery, will also contribute to the provision of higher quality of care.
CHAPTER 3
METHODOLOGY

Introduction

This chapter will include an overview of the study design and procedure, as well as interview information. Procedures for data management will also be discussed, along with limitations of the study.

The purpose of this study was to explore the lived experience of males who have been diagnosed with breast cancer. The focus of the research was from the time that symptoms were first noticed until one year post-diagnosis. While the majority of treatment is completed during the first year, it is also during that timeframe that significant adjustment issues may arise (Friedewald & Buzdar, 1997). It is hoped that gaining an understanding of this experience will assist nurses in providing optimal care for male breast cancer patients.

The study explored the following questions: 1) What meaning may be found in the lived experience of being diagnosed with male breast cancer? 2) How does the diagnosis of breast cancer affect one's life? 3) What effect does support of family/friends have on the experience? 4) What role does the spiritual/belief system play? 5) What factors influence decisions to seek treatment or cause delay in seeking treatment?
Study Design and Procedure

A qualitative design using a phenomenological approach based on the philosophy of Maurice Merleau-Ponty was used in this study. A phenomenological approach was selected as it allowed an in-depth look at each participant’s unique experience related to the phenomenon of being diagnosed with breast cancer. Insights were gained related to perceptions, actions, memories, and meanings. Utilizing this approach allowed concentration on the phenomenon from the participant’s perspective alone. Exploration of memories and meanings through the viewpoint of the study participant allows for a deeper understanding of the experience (Creswell, 1998).

Six men who had been diagnosed with breast cancer were interviewed. Interviews continued until the information being obtained was only serving to confirm previously collected data, with no new information being obtained. This is known as data saturation (Streubert & Carpenter, 1999).

Criterion sampling must be used in a phenomenological study (Creswell, 1998). Each participant was required to meet the following conditions:

- had been diagnosed with primary breast cancer
- was male
- spoke, wrote, read, and understood English
- was diagnosed in the year 2000 or later
- was diagnosed at least one year prior to the date of interview.

Participants were excluded from participation in the study for the following reasons:
• the cancer originated in another area of the body and metastasized to the breast
• there had been a previous diagnosis of another primary cancer, with the exception of skin cancer
• there had been a previous diagnosis of breast cancer.

Study participants were identified by four midwest hospital tumor registries as males having been diagnosed with breast cancer in the year 2000 or later. Study participants could range from Stage 0 to Stage 4 disease. A total of fifteen potential subjects were contacted by the hospital tumor registries, although it is unknown how many men were on two or more registries. (One man stated that he had been contacted by the tumor registries of two different hospitals.)

The first contact was a letter written by the investigator to educate the potential participant about the study and to invite participation in the study. A consent form was included with the initial letter. The consent form was mailed back to the hospital tumor registry by those who wished to participate in the study. In the case of those who did not respond, a follow-up contact was made by the tumor registry personnel. The second contact was either in the form of a reminder letter or a phone call to ascertain whether the person received the mailing, and to ask if there was interest in participation. If there were questions about the study, they were answered based on study information provided to the tumor registry by the investigator. Further questions were to be referred to the investigator, although there were no questions that required referral.
As soon as the signed consent was received by the hospital, contact information was provided to the investigator by tumor registry personnel. Potential subjects were individually contacted by phone and arrangements for an interview were made. The interview was arranged to take place at a site agreeable to both subject and investigator, and three of the interviews took place in the participant’s home. Other interview sites included a hotel conference room, a business office, and a university conference room. At the time of the interview, each participant received twenty-five dollars in cash as a token of appreciation.

Seven men signed a consent to participate in the study, but only six were interviewed. The seventh man agreed to an appointment for an interview in his home, but did not open the door when the investigator arrived. At the appointed time of the interview, someone could be heard inside the house quieting the dog, but no one came to the door. There was no response to further attempts to contact the potential participant.

Each subject was interviewed once. Based on the initial interview, an option was left open to conduct additional interviews, if needed for clarification or verification of information. Only one second contact was needed, and it involved a brief telephone call to the participant to clarify his answer to a question. Interviews were expected to be approximately 90 minutes in length, although they could have been terminated earlier if necessary. Actual interview time ranged from thirty to ninety minutes. Each interview was recorded, using two digital recorders to ensure that at least one recording was obtained. The
interview was transcribed verbatim using a speech-to-text software program, and the text and original recording were compared for accuracy by the researcher.

Field notes were also used by the investigator during the course of the interview for later use in data analysis. Field notes may be used to record observational or interview data (Morse & Richards, 2002). Information such as non-verbal communication or researcher thoughts that would not be captured on an audio tape were recorded as field notes to assist the researcher in preserving a more detailed recollection of the interview when conducting data analysis.

Interviews were conducted as soon as possible after receiving a signed consent. The process of data analysis was conducted upon the completion of each semi-structured interview, so that the emerging picture of the life experience of the participants could unfold as further interviews were arranged. Data collection continued until saturation was reached.

The investigator's role in the qualitative research process was integral to the procedure and outcomes of the study. The successful gathering of data hinged on the investigator's interaction with the participant. The investigator, therefore, was a determinant of the outcome of the study.

According to Thomas and Pollio (2002), the successful interviewer must keep in mind that the interviewee is the true authority in the subject matter being discussed. The investigator in this study, therefore, attempted to lay aside any pre-conceived ideas to learn from the participants about the experience itself. Similar to the way that a blank canvas evolves into a work of art (Merleau-Ponty, 1948), the phenomenological inquiry develops into a thing of beauty with the
colors that come from the subjects themselves. Colors added from the investigator, rather than from the study participants, would taint the art and damage the emerging picture. Although the investigator in this study had knowledge related to breast cancer itself, she did not have firsthand knowledge related to the male breast cancer experience. Remaining open and receptive to the knowledge being gained was, therefore, not exceedingly difficult.

Semi-Structured Interview

Information was shared by the participants during a semi-structured interview, thus contributing to the development of an understanding of the experience of being diagnosed with breast cancer. During the interview, physiological, psychological, spiritual, and social issues were explored.

A laddered question technique, as described by Price (2002), was used during the interview. Laddered questions move between three levels of inquiry. The first level is action questions, considered to be minimally invasive and used to gather information that is considered non-threatening to the participant. This level of questioning is often used at the beginning and ending of the interview, and is also useful for assisting the participant to relax or to decrease tension. An example of an action question that could have been used during the interview is, “What did you do first when you received the diagnosis of breast cancer?” The second level of inquiry is knowledge questions. Knowledge questions, considered to be more invasive, are used when the participant has relaxed and is showing signs of being ready to explore the subject matter more deeply. An example of a knowledge question is, “What made you decide to take that
action?" The third level of inquiry, philosophical questioning, explores the participant's personal values and beliefs. Such questions are typically reserved for the latter part of an interview in which the investigator and participant are relaxed and engaged. An example of a philosophical question is, "How did that make you feel?" Questions related to personal philosophy are most productive when the investigator and participant have established a positive trusting relationship. It was anticipated that a sufficient relationship would be established throughout the course of the interview to allow questions at a philosophical level, and this was the case in each interview.

The interviews focused on the time that the participant first noticed symptoms of breast cancer through one year after receiving a medical diagnosis of breast cancer. It is typically during the first year that the patient completes the majority of treatment for disease and experiences significant adjustment issues related to the disease (Friedewald & Buzdar, 1997). The primary inquiry that was asked of study participants was "Please tell me about your experience of being diagnosed with breast cancer." Questions were also asked related to the individual's thoughts at the first sign of illness, as well as how those thoughts evolved after the diagnosis of breast cancer had been made.

Following the philosophy of Maurice Merleau-Ponty, probes were used to guide the interview into specific areas related to corporeality, habituality, temporality, and expressivity. Merleau-Ponty believed that one's body is the avenue through which one experiences the world. This view of corporeality was explored through the use of probing questions such as "How has the experience
of breast cancer changed the way that you view your self?” Habituality, the
tendency of the body to seek balance through establishment of routines, was
investigated through probes such as “Tell me how your daily life has changed
since your diagnosis with breast cancer.” Temporality, the tendency to
experience time by being consistently drawn toward the future, is thought by
Merleau-Ponty to be the reason that a person can never be truly present in the
moment. Probes such as “How has your perception of the past, present, and/or
future changed in light of your experiencing breast cancer?” were used to guide
the interview into the area of temporality. Connections between thought and
interaction with the world, through verbalization or body language, are known as
expressivity (Merleau-Ponty, 1945). Expressivity was explored through probes
such as “How have your interactions/relationships with others changed since
your diagnosis of breast cancer?”

There were also questions in the interview based on the health belief
model such as “What factors influenced your decision to seek treatment?” and “If
there was a delay in seeking treatment, what were the causes?” Information
related to any delays in seeking medical attention was explored.

Demographic information related to age, marital status, personal health
history, family history of breast cancer, socioeconomic status, health insurance
coverage, religion/spiritual belief system, activity level, disease status, support
system, ethnic group, education, and employment history were also reviewed.
Each question was asked to provide a broad picture of the participant’s
background, to add direction to appropriate areas of the interview, and/or to
evaluate how the individual’s experience compared with information found in literature.

The interview guide that was used with all interviewees was developed after review of literature and as a result of consultation with phenomenological researchers and doctoral student peers. The investigator’s professional experience also allowed her to have close contact with many female breast cancer patients, thus contributing to the development of the interview questions.

Pilot Study

A pilot study was conducted to ensure that the interview questions were appropriate and understandable, to assess the flow of the questions, and to allow the researcher to evaluate interview-related issues which may not have been identified without a pilot study. A transcript of the pilot interview was provided to dissertation committee experts. The interview questions, the data collection method, and the analysis method were then evaluated through discussion and comparison of findings. No significant changes to the questions or processes were found to be necessary.

The pilot study involved one male volunteer who had been diagnosed with cancer, and had consented to be interviewed by the researcher for the purposes described. The volunteer was educated about the study, he signed a consent to participate, and he received twenty-five dollars in cash as a token of appreciation.

The purpose of the pilot study was to explore the interview questions, the data collection method, and the analysis method. At the time of the pilot study,
there had not been any male breast cancer patients admitted to the study. Since
the man interviewed in the pilot study had been diagnosed with a different type of
cancer, his input into the process was very valuable. Results obtained from the
pilot study, however, were not included in the study itself due to his not having
experienced male breast cancer.

Data Management

Data analysis was conducted using a three-step process: Description, reduction, and analysis. As described by Sadala and Adorno (2002),
phenomenological description reflects the experience as described by the study participant. Phenomenological reduction involves reflecting on the content of the information provided by the participant. Themes related to the males’ experience of breast cancer were identified in the reduction process. Phenomenological interpretation involves arriving at broad categories of meaning, based on the themes identified.

To preserve consistency, the investigator evaluated all interview data, identifying themes and developing meaning categories. Themes and meaning categories were developed as a result of interviewer memoing (related to interviewer thoughts and observations), as well as cutting and pasting of information using Microsoft Word.

Themes and meanings were based on the information gleaned from the study participants themselves. As themes were identified, they were entered into a list of emerging themes, along with supporting data from the interviews. Themes that arose consistently from one interview to the next, and those that
arose in a variety of ways, were considered to be major themes. When no new themes emerged in the fifth interview, data saturation was considered to be reached. A sixth interview also failed to give rise to new themes, confirming data saturation.

Although analysis was ongoing as interviews were being conducted, the questions in the interview guide did not change throughout the course of the study. Findings that had emerged in previous interviews did help to shape data gathering and analysis, however. For example, one study participant stated that he believed humor had helped him to cope with the breast cancer experience. Information such as this, having come from the participants themselves, made the researcher more sensitive to the emergence of related information in future interviews.

To validate findings during the conduction of the study, the first three interviews were evaluated by the committee chair, in addition to the researcher's analysis. Feedback received from the second reviewer helped to shape analysis of future interviews. Data collection continued until data saturation occurred.

All data containing identifying information are kept in a locked file, and identifying information will be destroyed at the end of five years. Contact information was kept, with the permission of the participants, for possible future research studies. All participants agreed that they could be contacted for future studies.
Protection of Human Subjects

Research began after approval by the University of North Dakota Institutional Review Board, as well as approval by each participating hospital. A total of four hospitals were involved. Participants were eligible to take part in the study after being identified by the institution’s tumor registry as having met the study criteria. Participation in the study was voluntary, and each participant signed an informed consent form prior to participating in the study. Participants were informed that they could withdraw from the study at any time without penalty.

The only direct benefit to participating in the study was receipt of twenty-five dollars in cash, given in appreciation for participation. An additional benefit to the participants was the knowledge that they were contributing to research which would ultimately help other men who may be dealing with male breast cancer.

There was minimal risk involved in this research study. Participants could have experienced fluctuating emotions when recalling the circumstances surrounding their diagnosis with breast cancer, but this was not a significant issue with any interview. Recommendations for counseling or other support would have been made had the need arisen.

The identity of the participants is being protected. All information gathered during the study was kept in a locked cabinet throughout the course of the study, and will remain so for five years, after which it will be destroyed. Participants were assured that their information would remain confidential, and that no identifying information would be published with study results.
Rigor

Qualitative research offers the investigator opportunity to explore topics that are diverse and hard to measure. Because of the nature of qualitative research, it is often viewed as softer than quantitative research, since it results in a revelation of reality which may be neither generalizable nor replicable. There is also frequent criticism of qualitative methods as lacking explicit rules for achieving reliability and validity, therefore missing the mark when it comes to rigor (Burns & Grove, 1999). According to Sandelowski (1986), rigor within qualitative research needs to be defined differently because the outcomes desired are much different. Rigor within qualitative research is based on openness, adherence to a philosophical perspective, and thorough data collection, while rigor within quantitative research is based on conciseness, adherence to research design, and accurate statistical analysis (Burns & Grove, 1999).

According to Guba and Lincoln (1981), rigor within qualitative research may be evaluated by its truth value, applicability, consistency, and neutrality. Truth value, viewed as internal validity in quantitative research, is judged by the qualitative investigator as credibility. Truth value indicates that the information presented is faithful to the phenomenon being studied, is easily recognizable to those who experience or observe it, and is subject-oriented, not investigator-defined. The qualitative investigator must deliberately focus on his/her own actions and values, and must keep in mind that the investigator-subject
relationship may both enhance and threaten truth value, depending on how objective one is able to remain.

Applicability, viewed by the quantitative investigator in terms of external validity, is viewed as fittingness by the qualitative investigator (Guba & Lincoln, 1981). Applicability/fittingness emphasizes the importance of studying the phenomena in its natural setting, and is considered to need fewer controls than would be required in quantitative research. The qualitative investigator seeks to provide information that is realistic, although not generalizable. The sample therefore, to increase applicability, is selected to match the phenomena being studied, rather than trying to include a specific number of participants. Fittingness is achieved when findings are both meaningful and applicable.

Consistency, the third criteria identified by Guba and Lincoln (1981), is viewed in terms of auditability by the qualitative investigator, while the quantitative investigator would think in terms of reliability. Auditability is achieved when another investigator can follow the investigator’s paper trail and arrive at a comparable conclusion.

Neutrality is viewed as objectivity by the quantitative investigator, while the qualitative investigator attempts to achieve confirmability. Confirmability refers to the findings themselves, not to the stance of the investigator. Subjectivity through investigator involvement is valued and meaning is derived from the experience.

Care was taken in this research study to preserve rigor through remaining constantly aware of the importance of truth value, applicability, consistency, and neutrality. Although each of these factors was valued, truth value was more
difficult to prove, since there were no plans for member checking (returning to the
subject after the time of the interview to verify findings) in this study. To maintain
rigor, therefore, more emphasis was placed on applicability, consistency, and
neutrality. Applicability/fittingness was achieved by seeking realistic information,
selecting sample participants who had been diagnosed with male breast cancer,
and seeking meaningful results. Consistency was achieved by having another
investigator audit findings of initial interviews, with comparable conclusions
related to major themes resulting. Discussion of individual variations in
conclusions between the researcher and the second auditor resulted in
agreement on all major themes. When there were seemingly divergent opinions,
the processes that led to the conclusions in question were explored, and were
found to be both reasonable and understandable. Neutrality was achieved by
valuing investigator/participant interaction, as well as the participant-focused
study results.

Limitations

According to Mies (1983), there is no way to study a thing without
changing it. A limitation of this study, therefore, was the possibility that informants
would try to reveal information that they believed the investigator wanted to hear.
Maintaining an accepting and non-judgmental attitude, assuring the participant
that there were no right or wrong answers, and asking questions to clarify
thoughts and meanings helped to ensure that information accurately reflected the
perceptions of the study participants. There was also the possibility that
memories and perceptions could change through time and, although the
information would still be valid, it may not be an accurate reflection of perceptions at a particular point in the past.

Another limitation of the study was that the research was conducted with a fairly homogenous sample. All of the men were Caucasian residents of the midwest. This limited the amount of information specific to culture that could possibly have been gleaned from this study, had it included participants from different cultural backgrounds or geographical areas.
CHAPTER 4

FINDINGS

Introduction

The purpose of this study was to explore the lived experience of males who have been diagnosed with breast cancer. The study explored the following questions: 1) What meaning may be found in the lived experience of being diagnosed with male breast cancer? 2) How does the diagnosis of breast cancer affect one's life? 3) What effect does support of family/friends have on the experience? 4) What role, if any, does the spiritual/belief system play? 5) What factors influence decisions to seek treatment or cause delay in seeking treatment?

This chapter will present demographic information related to the study participants. Findings of the study will then be explored, including the themes and meanings that unfolded during the study. The organization of the themes and meanings will be based on the five research questions. See table below for the ten themes that were identified.
Table 1. Identified Themes

| Theme #1: Breast cancer was something to take in stride – deal with it and get on with life. |
| Theme #2: Humor and the quest for normalcy helped with coping. |
| Theme #3: Breast cancer served as a wake-up call and brought with it a sense of vulnerability. |
| Theme #4: Body image was minimally affected. |
| Theme #5: Negative outcomes were challenges. |
| Theme #6: Positive outcomes were blessings. |
| Theme #7: Changes in time perception were subtle and may have been unrelated to the breast cancer experience. |
| Theme #8: Social and spiritual support was meaningful throughout the breast cancer experience. |
| Theme #9: Delay in seeking treatment was multi-factorial. |
| Theme #10: Availability of more information would have contributed to increased autonomy. |

Demographic Information

There were six participants in the study. Each of the participants consented to participate in the study after being identified as meeting the study criteria by the tumor registry of a midwest hospital. After consent was received by the hospital, contact information was given to the researcher and interviews were arranged. The six study participants ranged in age from 54 to 81, and all were Caucasian. Time of diagnosis ranged from one year to five years prior to the interview. Four of the men were married, one was divorced, and one was widowed. Questions related to personal health history revealed that none of the
men in the study had significant co-morbidities, and none had a family history of breast cancer. All of the participants identified themselves as being financially secure, with the exception of one. All but one stated that they had adequate health insurance coverage through an employer or through Medicare with a supplement. Three of the men stated that they had a strong spiritual belief system, identifying closely with an organized religion. Two described themselves as spiritual beings, finding strength through activities including outdoor sports, reading, and quiet contemplation or meditation, but with little or no affiliation with a particular religion. One participant identified himself as an atheist, and did not view himself as spiritual in any way, but stated that he found strength in enjoyment of nature and living a good life.

All of the men stated that they viewed their activity level as normal for their age, and all identified their health status as being free of cancer. The two men who were under the age of 65 had a bachelor's degree and were employed in professional positions. One of the older men identified himself as retired, although he stated he wished he could still be working. The other older men were still working full- or part-time in sales or management positions, although they stated that they had control over their hours and were working by choice. One of the older men had a post-graduate degree, one had a bachelor's degree, and two had a high school education. Five of the participants identified their wives and/or families as their support system, while one of the unmarried participants stated he was his own support system, although he said he was also grateful for the support of his significant other.
The following table may be helpful in summarizing the demographic information:

Table 2. Demographic Data

<table>
<thead>
<tr>
<th></th>
<th>54, 56, 70, 75, 79, 81</th>
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</thead>
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<tr>
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<td>1, 3, 3, 5, 3, 5 (respectively to above ages)</td>
</tr>
<tr>
<td>Years Since Diagnosis</td>
<td>Marital Status</td>
</tr>
<tr>
<td>Marital Status</td>
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</tr>
<tr>
<td></td>
<td>Divorced – 1</td>
</tr>
<tr>
<td></td>
<td>Widowed – 1</td>
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<td>Financial and Insurance Status</td>
<td>Financially Secure / Adequate Insurance Coverage – 5</td>
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<tr>
<td></td>
<td>Financial Challenges / Inadequate Insurance Coverage – 1</td>
</tr>
<tr>
<td>Spiritual/Belief System</td>
<td>Involved in Organized Religion and Self-Identified as Spiritual – 3</td>
</tr>
<tr>
<td></td>
<td>Uninvolved with Organized Religion and Self-Identified as Spiritual – 2</td>
</tr>
<tr>
<td></td>
<td>Uninvolved with Organized Religion, and Self-Identified as Non-Spiritual – 1</td>
</tr>
<tr>
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<td>Semi-Retired – 3</td>
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<tr>
<td>Support System</td>
<td>Wife – 1</td>
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<td></td>
<td>Wife and Family – 3</td>
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</tr>
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<td></td>
<td>Master’s Degree – 1</td>
</tr>
</tbody>
</table>

Research Question One

The first research question asked what meaning may be found in the lived experience of being diagnosed with male breast cancer. Each participant was asked to identify a word or phrase that would describe the personal meaning of the breast cancer experience. Although the men each focused on a different aspect of the breast cancer experience when asked to assign a meaning, the life-altering results of the experience could be heard in their answers.
The answers given by the six men were as different as the six men themselves, yet each answer fit perfectly with the tenor of both the individual and the interview itself. The expressed meaning, in other words, was a true representation of the experience of each individual interview. The meaning of the cancer experience was summarized as follows by the six participants:

1- Lack of intelligence on my part. I should’ve known. We know how to do everything else, fix the car or whatever, but we don’t know how to care for ourselves. We’re like sheep following blindly – like if you have something, you go get a shot of antibiotic – instant cure. That’s what you want. And we live by that.

2- Just do what you can and go ahead with your life. Put your hands in God’s and all the doctors and support people, and just try to go ahead and do the best you can.

3- I would say that it has greatly increased my sympathy for other people’s suffering. I think when I hear about what other people are going through, I don’t think I could be that brave.

4- I think I’ll call it Bob (laughs). No, I’m just kidding with you. Humbling. The fact of my experience making me realize that I can succumb to disease. It makes you realize that you’re in the same playing field with all the rest of that humanity out there, you’re not out there someplace (gestures toward the distance). We’ll call it that.

5- Well, I guess it was kind of a wake up call – that life is not going to go on forever. So kind of enjoy each day that you can.

6- Humiliating. I’m not embarrassed by the disease, but by what it did to my physical appearance. I won’t swim and I won’t change clothes in front of anybody other than my wife.
Research Question Two

The second research question explored how the diagnosis of breast cancer affects one’s life. Several themes emerged related to this research question. The first theme involved the way that the men coped with breast cancer. They dealt with the disease by adopting the attitude that the breast cancer was something to take in stride, dealing with it and then getting on with life. The quest for normalcy and use of humor also emerged as means by which the men coped with their illness.

Another theme that emerged related to the second research question was that the disease served as a wake-up call, often resulting in significant life changes. A sense of vulnerability also emerged in relation to the wake-up call.

Although each of the men in the study denied that the cancer had been of major significance in day-to-day life, they also discussed ways that they had changed as a result of the breast cancer experience, indicating that the disease actually had been life-altering. Although negative outcomes were generally downplayed by the men, change in body image was the negative outcome that was identified most often by the study participants. Positive outcomes were also identified, as well as subtle changes in perceptions related to time.

Theme #1: Breast cancer was something to take in stride – deal with it and get on with life.

All of the participants in the study agreed that breast cancer needed to be incorporated into life – that it was just another thing with which a person had to deal. One participant said:
It's kind of funny, but I don't consider that breast cancer significant. And of course you go through denial, anger, acceptance. I guess there wasn't much anger. It was just—okay, you got it, now what are we gonna do about it? It was just kind of something else to take in stride. It really hasn't affected my life since it turned out so well. I don't really think it's affected my life at all. I do everything that I've always done.

Another participant stated, "I didn't really think anything about it. I knew it was a battle to be fought." A third man put it this way:

It wasn't the ordeal that I thought it would be. It wasn't like it was that earthshaking. It took a little chunk out of my year, out of my schedule. It turned my life around 360 degrees and I'm still going in the same path. Basically, once it was past and I healed up and I had it behind me, everything pretty much bounced back to normal. I don't see any real big changes. It wasn't world-changing.

Theme #2: Humor and the quest for normalcy helped with coping.

As the men described their experience with breast cancer, there was no mention of personal sadness related to the disease. Each interview was interspersed with laughter as the men related how they had incorporated humor as a coping strategy. One man stated:

Toward the end of radiation, I did get some pretty bad burning, skin weeping, and peeling off. It was like a really bad sunburn. The first treatment I had, I came out and my wife was giving me the funniest look. She said, "Are you extra crispy or what?" But it turned out one of the nurses had burned popcorn in the microwave back there. But my wife thought I was smoking or something.

Actually, I found once I got into the treatments, it was almost like kind of an adventure in a way for me. We had fun with it. We had the oncology nurses entertained a lot... I thought about getting an eyeball tattooed where the nipple used to be. My supervisors were extremely understanding. I called one up and he was laughing because I called and left him a message that I wanted to keep him "abreast" of the situation. He giggled about that.
Another participant told of an incident when someone jokingly pretended that she was going to pinch his nipples in a social situation. He told her that he didn’t have a nipple on that side. She laughed and moved along as he was starting to pull up his shirt to show her. He expressed disappointment that the joke was over before he got to see her reaction. This participant further stated that his reaction to others about the breast cancer is “What the hell? You know, I have something really odd going on. I’m a man who has had breast cancer. What do you know about that? (laughs) Wanna see my scar?”

Several participants shared that the quest for normalcy was helpful in their coping with the disease. One gentleman stated, “You know, it goes past, and you move back to normal again. I feel like it’s all normal now. It’s not changed or impacted.” Another participant summed it up by saying, “It wasn’t really too upsetting. I was doing everything pretty normal. I said, ‘Let’s do whatever we have to do to get rid of it’ and tried to live as normal as I can.”

*Theme #3: Breast cancer served as a wake-up call and brought with it a sense of vulnerability.*

One participant shared that the experience of breast cancer had made him realize that his priorities needed to be adjusted. He stated:

*It made me realize that my health is something more to be prized and guarded than I’ve really done. I just haven’t really thought about health a whole lot until this. It also makes me realize that life is short. Live it to enjoy it. I’ve always kind of believed in that, but it kind of brings it home to you... It made me kind of think about what’s important, what’s valuable, and kind of reevaluate my priorities a little bit.*
Breast cancer really hasn't changed the way I do things very much. I think it was maybe a little bit of a wake-up call. I'm a little more appreciative of how fragile life is. Life is not going to go on forever. So kind of enjoy each day that you can. Stop and smell the roses, I guess.

One of the men who was in his seventies stated, "Well, you see, I was never going to die. I am a little more appreciative of how fragile life is and what it could have been. Kind of a sense of vulnerability. " A third participant eloquently explained:

I'm not ten feet tall and bulletproof anymore. I think a lot of us when we're young, we go along as though we are not vulnerable. Either you're convinced you're not going to live to be thirty or, you know, the idea of having a disease is just so far away and far off that it's not even there. I realize now that I am vulnerable.

Theme #4: Body image was minimally affected.

All six of the men in the study had experienced a mastectomy as the surgical portion of their cancer treatment. Five of the six study participants acknowledged that there was an effect on body image related to the cancer surgery and/or radiation, although all of them downplayed the significance of the changes. Although some acknowledged that they were personally affected to some extent by a change in body image, there was also concern expressed about how their appearance would be viewed by the public eye.

Most of the men stated that they were a little bit hesitant to remove their shirts in public, and several admitted that they had cut back on or eliminated swimming from their lives. One man, even though he downplayed the significance of the change in his body image, said that what the disease had
done to his body was "humiliating." He gave up swimming, but stated that it was not a big issue, as he probably would have given it up due to his age anyway.

The oldest study participant stated, "I get a lot of compliments on the job (surgery results). The doctor did a nice job. I don't have the chest I used to have (laughs). I don't have the physical makeup that I used to have. I guess that don't bother me much."

Another participant stated:

I maybe struggled with my body image a little at first. You don't go around with your shirt off (laughs). And kind of reluctant to get into a swimsuit or something. But it hasn't bothered me personally or anything like that. I do get in a swimsuit once in awhile now.

One of the younger participants explained:

I don't think my body image has really suffered any. I was never very vain about my body. I don't go swimming or anything like that. I guess I'm not really exposed. I suppose I might be a little bit self-conscious, like if I was swimming or something, but I haven't, I guess.

Another gentleman, who was in his seventies, stated:

The only changes that I can say is that I don't run around without a shirt on, which I always used to, but then I don't think a 70-year-old man should run around without a shirt anyway (laughs), but that's beside the point... It really hasn't affected my life at all really, I just forget about it -- other than the fact I don't swim anymore, you know, like that. Well, I take that back, I have gone swimming a couple of times, but I've got a mesh (looks down at chest) -- because I don't think it looks very good -- but I've got a mesh tank top and it kind of matches the swimsuit... But I don't really think it's affected my life at all... Unless you're a Chippendale dancer, it's not really going to affect you anyway. Maybe a much younger person it might.
Theme #5: Negative outcomes were challenges.

One participant identified negative outcomes that he believed were related to his radiation. He stated that he was having issues related to body function that prevented his being able to travel, something that he and his wife had enjoyed in the past. He explained that he had been unable to travel for four years, but that his wife was very supportive of him, having adjusted to his limitations. He was convinced that the health issues with which he was dealing were the result of “overcooking” with radiation, as he was told by his physician that perhaps the chronic redness in the irradiated area was due to excessive radiation. He had not addressed his ongoing symptoms with any of his doctors, stating that he was looking for answers himself related to what caused the cancer and what could keep it from coming back. He was also seeking restoration of normal body function through expensive herbal alternative therapies. He stated that he had begun to see improvement and was convinced that his chosen therapy route would be beneficial. (He was encouraged by the researcher to discuss his health issues with his physician, but he did not commit to doing so.)

Another participant experienced severe financial hardships as a result of the breast cancer. His place of employment closed during his cancer treatment, and his health insurance was lost. He found it difficult to find employment again after his treatment period. He believed that the difficulty in finding employment was due to his age, as well as to the fact that he had developed lymphedema, which he described as a factor in his losing a position after only a week. He stated:
The first nurse said I passed my physical and she didn't think my arm would affect my job. But then another nurse came through, saw the arm, and knew what caused it. They called the day after that and let me go... The aftermath was far worse than the [cancer] treatment actually. You know, just being rejected for one job after another... When you're looking for a job in your fifties, you don't exactly have people beating down the door to hire you either... With us, it's not so much self-image and all that that happened. It's trying to pick up the pieces afterward... The aftermath is what was worse than the disease. (Wife then states, "You're broken and you're not worth having anymore... It's a helpless feeling.")

**Theme #6: Positive outcomes were blessings.**

Study participants were thankful for positive changes that came about as a result of their breast cancer experiences. Many expressed development of a sense of gratitude for having come through the experience so well. One participant explained:

I think there's definitely BC and AC – before cancer and after cancer. I've probably changed more than I know. I can't really say that I've... like some people [say], "Everything changes and I'm going to climb Mount Everest now" or whatever. There's nothing that grand or anything... I think I enjoy people more now. I'm more patient and tolerant... I think in some ways, I feel a little braver as a result of this experience. I even learned how to drive. I always had a phobia about it... When it began, I had no idea whether I would survive this or not, but I feel like if I got through that, I can get through just about anything.

Another participant stated:

I was really lucky. I didn't have to have any chemo. We caught it early enough. It was about the size of a golf ball... There was nothing in the lymph nodes or anything.... I was really never sick. I never felt, you know, I didn't go through all the torture and the chemo... I'm sure if there had been more serious problems with it that it would change your outlook altogether.
A man who did go through chemo stated:

I was just relieved after surgery that they got everything, that it hadn’t spread to my lymph nodes other than that microscopic amount in the first one. I was expecting the pain to be worse, but it wasn’t as bad as I expected it to be... I was terribly disappointed because they were going to give me four rounds of chemotherapy at first, then I had to have six. I was very disappointed because of those extra two. But then I hear stories about people taking chemotherapy every week, so it wasn’t so terribly bad... I didn’t have too much trouble with nausea. In fact, I felt so sorry. They gave me the three last samples of those [new nausea] pills. Then there was a lady next to me in the chemotherapy and I overheard them say, “We just gave the last three out.” She was just starting her chemotherapy, so I got out of my car and I told my wife, “My conscience is bothering me.” So I went back in and I gave her a couple... I realize that I got off lucky, and it has made me aware of what other people are going through in their cancer treatment.

One of the younger participants experienced hot flashes as a result of his treatment with the drug tamoxifen. He laughed as he said, “Yeah, I did have hot flashes. [My wife] and I shared hot flashes. Not something that every couple can say...”

Theme #7: Changes in time perception were subtle and may have been unrelated to the breast cancer experience.

Study participants identified ways in which their view of time had changed, possibly as a result of their breast cancer experiences. There was general agreement, however, that the changes in time perception could have been due, in large part, to the everyday experience of aging. Their agreement in this area is interesting, considering their ages range from 54 to 81 years.

Regarding his view of the past, one study participant discussed difficulty of past times, as well as the uncertain future of the country. He stated:
Our lives have pretty much been for our kids — giving them a good start, treating them right, respectfully, and give them every chance that they have to make it. And that’s what we did... We are happier, I think, than a millionaire, because that’s all they live for is money. If that’s all you live for, you ain’t going to have much to live for here before very long. But I would like the kids to do well. Cancer has nothing to do with that.

One participant, in looking back at the past, stated that the breast cancer experience caused him to question what he had done with his life. He wondered aloud whether he should have done “so much more.” Another participant stated that he cherished his memories of past times and past relationships more.

Regarding the view of the present, most of the participants believed that their day-to-day life was different, but they did not believe that it was due to having experienced breast cancer. Most believed that the subtle changes were, at least in part, related to the normal aging process.

The oldest gentleman in the study stated:

I've slowed down and before I'd go full-bore all day long. Well, then it (breast cancer) knocks you down to where you really can't — you get very tired and I notice time now gets away from me, whereas before I pretty much could handle it. Everything I wanted to get done in the length of time I had to do it. Now it gets away from me, and I don't care... [My] view of time has changed more in relation to everyday life rather than to breast cancer.

Another gentleman stated:

I take it more easy maybe. I get tired a little quicker, but I keep thinking that comes with the territory... Maybe I take it more easy just related to other things in life, rather than to the breast cancer... I don't think it really had all that much effect.

One of the younger participants revealed:

I often say to myself, “Life is too short.” I try not to get worked up over petty things. But I still do. I'm still human... I think I've actually become a little bit more solitary, and I don't rely much on
friendsnip... I should [work on building relationships], but I’ve been so busy at work. So when I have a day off, I really don’t want to do anything. I have become pretty independent. I guess I just don’t do a lot of socializing. I never really have... It’s kind of hard to tell at our age. We have a midlife crisis and it’s hard to tell what contributed – how to make the evaluation.

As for the future, none of the participants revealed that breast cancer played a major role. Two of the men mentioned the possibility of breast cancer recurring. They indicated that they would face it matter-of-factly, taking it as it came. Both said that fear of recurrence did not influence their perception of the future.

Another man, in discussing his outlook on the future, stated, “I’ve never been afraid of dying. Afraid of dying, but I’ve never been afraid of dying of this disease, because I just don’t think it’s going to get me... It’s something to get over with and forget about... You just move on.”

Research Questions Three and Four

The third research question asked what effect support of family/friends had on the experience, while the fourth question asked about the role of one’s spiritual/belief system. Throughout the data collection period, it became very evident that these two questions were strongly interrelated. Because of their being so intertwined, there was evident overlap in the discussion of research questions three and four, so both are discussed in this section.

Theme #8: Social and spiritual support were meaningful throughout the breast cancer experience.

Regarding the effects of social support, all of the study participants voiced appreciation for those who had supported them. Those who were married
mentioned spousal support as being the most important resource in their support system. One participant mentioned appreciation for his mother’s support, and others mentioned support of children and close friends. All of the men denied that breast cancer had affected their personal relationships, and the support activity mentioned most often by study participants as being appreciated was “being there.”

One gentleman voiced appreciation for his wife and family, and also addressed the support that was offered to him by those who were not friends or family. He stated:

My wife was my biggest source of support. She saw me through a lot and I had friends who were good about coming to the hospital... The people I worked with were very supportive and encouraging and kind through the whole thing... As far as groups and things, they gave me all the information about the organizations I could contact to provide counseling and such. I’m just not a joiner... A lot of information was given to me about other men who had breast cancer, which I did talk to a couple of them and just kind of talked about their experience. See how they were doing and everything. But I thought – okay, we both have breast cancer, but I don’t know you and you don’t know me. Not to take away from it at all, I mean it’s a wonderful thing, the support that’s available for people who do want to partake.

The role of health care personnel was also mentioned as being important to support by four participants. They mentioned finding it helpful when doctors and nurses gave support such as being available, offering humor, and establishing a sense of camaraderie. One sportsman, for example, voiced appreciation for a surgeon that enjoyed hunting. He said the surgeon “thought he was my ouddy” and “showed a lot of concern.”
One participant voiced appreciation for the support of the chemotherapy nurses. He especially enjoyed their joking with him and his wife, helping to put them at ease. At times, however, he stated that they made him feel somewhat uncomfortable through what he considered inappropriate humor. He stated:

The nurses would tell us horror stories, and we wouldn’t freak out or anything. They did a good job and everything. Of course, sometimes I wonder, I had a port put in... and one of the nurses said that a nurse missed the porta-cath and then the patient’s chest cavity filled up with that – I see this skull and crossbones on the [chemo] bag – and all of her skin peeled off and everything. And I thought, my goodness, I’m having this done to me right now. But my nurses always made sure to see blood come out first, so they’d know they had it.

Regarding effects of the spiritual/belief system, three of the study participants identified themselves as being spiritual and following an organized religion. They indicated that their individual belief systems brought them comfort and strength. One of the participants stated:

I made peace with my Maker when I was in the service and I never went back on it. I thought that it (going through treatment) was the right thing to do as long as I felt good about it. In other words, I was getting His permission to go ahead. I feel that my faith was a source of strength through all this.

Another gentleman stated:

My personal faith helped me through this. I belong to the Presbyterian Church and there are prayers in the church and support at home... [You] put your hands in God’s... and just try to go ahead and do the best you can.

One person who did not identify with any organized religion identified himself as a spiritual being. He explained that he also found strength through spiritual support, saying:
I'm kind of a terrible person. I'm not religious at all. I strongly believe in the teachings of Christ. Treating people as you would have them treat you, all the basic tenets I believe in. That's the way I was raised. My family wasn't a strongly religious one by any means. It was like, you have to get the kid confirmed, you know, but they've never been to church themselves. It's depressing. So, I grew up with not a particularly fond attitude toward organized religion... I take a lot of comfort from nature. When I was going through chemotherapy, we'd sit out under our big cottonwood tree in the front yard, and we'd go through the rosary. That was kind of my form of meditation. I never learned the rosary. My wife had to say it, and that had a very calming effect... I appreciated the things that the church did for me. The Catholic Church put me on their prayer list. I appreciated that. I don't know if I'm a strong believer in prayer. I don't know if it really works, but people swear it does. It certainly works for people who are praying. It makes them feel better.

Another participant who was not involved with organized religion stated:

Religion did not play a big personal role for me going through the cancer. I'm not as religious as my mother is. She told me I'd better start thinking about the hereafter. I believe there is a God, yes. I love the outdoors, and all of that beauty that I see. I don't think it just happened. I gain a lot of strength from being in the outdoors.

A participant who identified himself as being non-spiritual stated:

I consider myself more or less to be an atheist. I don't believe in the standard cultural traditional religions. When my family and friends said they were praying for me, I just said, "Thank you for your kind thoughts." And I'm appreciative of that, you know. It's their way of expressing and that's cool... I find peace in myself, in just living my life well, and trying to do good. I think I draw my strength just in myself. I'm kind of self-sufficient.

Research Question Five

The fifth research question asked what factors influenced decisions to seek treatment or caused delay in seeking treatment. All of the men in the study stated that they had discovered the indication of breast cancer themselves – some by noticing a lump, and some by noting a diversion of the nipple. Three of
the men in the study sought treatment without significant delay, going to the clinic to have the area evaluated within a matter of a few weeks.

Theme #9: Delay in seeking treatment was multi-factorial.

One of the men stated that he ignored the symptoms for several months, believing that it was “just something to watch.” He further explained, “There wasn’t any reason I delayed going in to have it checked other than thinking it was just something that wasn’t too serious.” Toward the end, he noted that it had grown to where he could “feel it bounce” when he was riding his bicycle. Even at that point, he did not have the breast evaluated. He said, “I think I just went in for physical and I mentioned that, and that was the end of the physical. We went to the x-ray and then we did a biopsy and then the biopsy came back positive.”

Another man stated that he waited about a month to go in. He said that it was on his mind, but that he was a procrastinator and had no particular excuse for delaying medical treatment. Another man said that his doctor had been “pushing on those lumps for years.” Even when his nipple turned, the surgeon told him, “You can do this [biopsy] if you want to or you don’t have to.” His pathology report revealed that 26 of the 27 lymph nodes that were removed were positive for cancer.

Two of the men who had delayed seeking treatment indicated that they believed they needed to have a significant reason before seeing the doctor. One who is still experiencing health problems that he attributes to the radiation stated, “But I have to have an excuse to see [the doctor].” He did not believe that his current health concerns were significant enough to warrant a visit to the clinic.
Additional Theme

Theme #10: Availability of more information would have contributed to increased autonomy.

An additional theme that arose as a result of the research was related to the need for more information about male breast cancer and treatment options. The study participants indicated that lack of knowledge decreased their ability to make informed decisions. This affected not only their decision to seek treatment, but also the course of treatment that they chose.

One interesting area that evolved was the revelation that three of the six men in the study stated they would have done things differently if they could go through the experience again. One man stated that he would have looked for more information, and that he would have refused radiation. The other two men stated that they would have pursued less aggressive surgery or changed the type of chemotherapy received. All three said that they would take more control if they had it to do over again. Two expressed lack of confidence in their physicians, and one asked the researcher, with whom he had been talking for one hour, if she would consider becoming an oncologist, stating, “I trust you.”

In addition, five of the six men in the study stated that they did not know that men could get breast cancer prior to experiencing it themselves. Three of them said that their wives or girlfriends were aware, and that they were encouraged to seek treatment by their significant others. One of the unmarried men stated:

One doesn’t think of a man getting breast cancer. Had people sat down and discussed it or made mention of it, I probably would
have had the opinion that men could [get breast cancer], because I know that men have breast tissue. So I guess if we'd thought about it, I probably would've speculated that, yes, men can get breast cancer, but it just wasn't a topic that came to mind.

Another man said:

No, I was not aware that men could get breast cancer. To me, it was kind of like, can men have babies? I like ladies, but I don't need their health problems... How do you get breast cancer if you don't really have breasts?

Summary

The purpose of this study was to explore the phenomenon of the lived experience of males who have been diagnosed with breast cancer. The study explored the following questions: 1) What meaning may be found in the lived experience of being diagnosed with male breast cancer? 2) How does the diagnosis of breast cancer affect one's life? 3) What effect does support of family/friends have on the experience? 4) What role, if any, does the spiritual/belief system play? 5) What factors influence decisions to seek treatment or cause delay in seeking treatment?

This chapter explored the phenomenon of being diagnosed with male breast cancer, as described through the views of each individual study participant. The themes that emerged, as they related to each of the study's research questions, were discussed. An overall viewpoint that was shared by the study participants was that the breast cancer experience was not considered to be significantly devastating or life-changing, although the statements of the men themselves often contradicted this expressed viewpoint.
CHAPTER 5
SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Introduction

This chapter will present a summary of the research study, as well as conclusions drawn from the findings of the study, as outlined in Chapter 4. Implications related to the study findings will be discussed, and recommendations for further research will be offered.

Summary of the Study

Breast cancer continues to be a major health concern in the United States, with almost 200,000 new cases diagnosed yearly. Although approximately one percent of those who are newly-diagnosed are male (American Cancer Society, 2007), there has been a relatively small amount of research devoted to the needs of this group.

The purpose of this study was to explore the lived experience of males diagnosed with breast cancer. The focus of the research was intended to be from the time that symptoms were first noticed until one year post-diagnosis, as completion of treatment typically occurs during the several months after diagnosis. Although it is during that first year that patients face significant adjustment issues (Friedewald & Buzdar, 1997), this study did not stop its inquiry at the one-year margin. It became apparent during the course of the study
that information encompassing the time period after the one-year recovery period also contained valuable information. Since all of the study participants had been diagnosed at least one year previously, and not more than five years had passed since their diagnosis, it was decided that exploration of the second through fifth years post-diagnosis would also make an important contribution to the study findings. The overall hope in conducting the study was to gain an understanding of the experience of being diagnosed with male breast cancer that would assist nurses in providing optimal care for male breast cancer patients.

The study explored the following questions: 1) What meaning may be found in the lived experience of being diagnosed with male breast cancer? 2) How does the diagnosis of breast cancer affect one’s life? 3) What effect does support of family/friends have on the experience? 4) What role, if any, does the spiritual/belief system play? 5) What factors influence decisions to seek treatment or cause delay in seeking treatment?

The study aim was accomplished by conducting a semi-structured interview with each of the six study participants that had been identified by a midwest hospital as meeting the study criteria. After the signed consent was received by the hospital, contact information was provided to the investigator and potential subjects were individually contacted by phone to make arrangements for an interview. Three of the interviews took place in the participant’s home, one took place at the participant’s place of business, one was conducted in a hotel conference room, and one transpired in a university conference room. All of the participants were Caucasian males, and their ages ranged from 54 to 81.
This qualitative study used a phenomenological approach that allowed the investigator to collect data according to the views of the men themselves. The information was shared by the participants during a semi-structured interview, thus contributing to the development of an understanding of the experience of being diagnosed with breast cancer.

The philosophical underpinnings of the study followed the philosophy of Maurice Merleau-Ponty. Probes were used during the semi-structured interview to guide the discussion into specific areas related to corporeality, habituality, temporality, and expressivity. Although specific probes were used during the interview process, the intent of the phenomenological inquiry is that the data emerge from the subjects’ rich descriptions of the phenomenon itself. The researcher’s thoughts and ideas, therefore, are to be bracketed in this type of study, allowing the findings to emerge without undue influence from the researcher (Gearing, 2004).

The process of phenomenological inquiry, according to Merleau-Ponty (1948), may be considered similar to the way that an artist assists a blank canvas to become a piece of art. It is described as follows:

The rules of anatomy and design are present in each stroke of the brush just as the rules of the game underlie each stroke of a tennis match. Motivating all the movements from which a picture gradually emerges there can be only one thing: the landscape in its totality and in its absolute fullness. Starting by discovering the geological foundations of the landscape, [the artist] halts any looks at everything with widened eyes, ‘germinating’ with the countryside. The task before him is, first to forget all he had ever learned from science and, second, through these sciences, to recapture the structure of the landscape as an emerging organism (p. 17).
Each interview was recorded, and was then transcribed verbatim using a speech-to-text software program. The text and original recordings were compared for accuracy by the researcher. The interviews were then read and re-read several times, immersing the researcher in the interview data. The field notes made by the investigator during the course of the interview, as well as memoing of thoughts and ideas during the re-reading of interviews, contributed to the emergence of themes. Meanings related to the themes then developed as analysis continued.

Data analysis was conducted using the three-step process described by Sadala and Adorno (2002): description, reduction, and analysis. Phenomenological description reflects the experience as described by the study participant. Phenomenological reduction involves reflecting on the content of the information provided by the participant. Themes related to the males' experience of breast cancer were identified in the reduction process. Phenomenological interpretation involves arriving at broad categories of meaning, based on the themes identified.

Data analysis was ongoing throughout the data collection process. Data collection continued until it was apparent that saturation had been reached with the fifth interview, when there were no new themes that emerged. A sixth interview was then done to complete the data collection process.

To preserve consistency, the investigator evaluated all interview data, identifying themes and developing meaning categories. In addition to the researcher's evaluation, the pilot interview was also evaluated by the dissertation
committee methodology expert to ensure soundness of analysis techniques. The first three interviews were evaluated by the committee chair, in addition to the researcher's analysis. Feedback received from the second reviewer helped to shape analysis of future interviews. All further interviews were submitted to the committee chair for feedback related to interview content and analysis.

Findings in the study included the emergence of the following ten major themes:

1. Breast cancer was something to take in stride – deal with it and get on with life.
2. Humor and the quest for normalcy helped with coping.
3. Breast cancer served as a wake-up call and brought with it a sense of vulnerability.
4. Body image was minimally affected.
5. Negative outcomes were challenges.
6. Positive outcomes were blessings.
7. Changes in time perception were subtle and may have been unrelated to the breast cancer experience.
8. Social and spiritual support was meaningful throughout the breast cancer experience.
9. Delay in seeking treatment was multi-factorial.
10. Availability of more information would have contributed to increased autonomy.
Findings Related to the Literature

The first research question asked what meaning may be found in the lived experience of being diagnosed with male breast cancer. Current literature does not offer a clear picture of what meaning may be found in male breast cancer. Several studies are available that explore meaning in the female breast cancer experience. One qualitative study, for example, conducted by Coward and Kahn (2005) explored the way that women create meaning from their breast cancer experience. One of the key factors involved in the creation of meaning in the Coward and Kahn study was involvement in supportive social environments. A study by Collie and Long (2005) also discusses the importance of the social support context in formulating meaning from the breast cancer experience.

Literature does not offer solid guidance, however, related to exploring the meaning of breast cancer when men are the ones who are experiencing the illness. The men involved in this qualitative study did not express an interest in seeking support from other men who had experienced a similar situation. Although the wife of one of the men in the study stated that she thought it would be good for her husband to be involved in a support group, he himself had a different idea. He stated that he wouldn’t be interested in being involved with a group of men that he didn’t know. He believed that having experienced a similar health situation was not enough to cause him to want to be involved with other men in a social or support context.

The role of social support in the formulation of meaning in the male breast cancer experience is therefore, at best, unclear. There is insufficient literature to
guide one's thinking in this area. Based on this qualitative study, however, it seems clear that one should not make assumptions when comparing and contrasting the male and female experience of formulation of meaning, as the male experience may follow an entirely different path.

Interestingly, all of the participants in the study shared examples of how the disease had changed their lives, yet they expressed that they did not believe the breast cancer had been of major significance in their lives. This, too, leaves questions when compared to literature. Leonard (2004), for example, discusses how the diagnosis of male breast cancer may lead to feelings of isolation, disempowerment, and a decrease in feelings of masculinity due to a diagnosis with what may be considered a female disease. Suhanic (2005) also addresses embarrassment that can be so significant that it will prevent a man from seeking treatment for his symptoms. Even though some of the participants stated that they would no longer appear shirtless in public, and one man stated that he believed the disease was humiliating, the men consistently downplayed the significance of the disease.

One of the men in the study referred to breast cancer as a disease that pertained to "ladies," yet he said that he was not embarrassed by it. Another man, whose wife participated in the interview, agreed when she stated, "He's got a totally different attitude from what we were told that a lot of men have, and that's the ego thing and having a woman's disease. That never bothered him. He's never been on a macho trip or anything." He then responded by saying, "I try not to be. I never felt any shame or any social thing like that."
Although each of the men in the study denied that the cancer had been of major significance in day-to-day life, they also discussed ways that they had changed as a result of the breast cancer experience, indicating that the disease actually had been life-altering. Even when using adjectives as strong as "humiliating," they downplayed the effects of the disease. This paradox was somewhat surprising to the researcher, even though she had done her best to bracket previous knowledge and opinions. It seemed that the disease had significantly affected their lives, yet they consistently denied its impact on them.

The second research question explored how the diagnosis of breast cancer affects one's life. Although they admitted that the disease had served as a wake-up call for them, the men in the study coped by adopting the attitude that the breast cancer was something to take in stride, dealing with it and then getting on with life. They sought to restore a sense of normalcy and to maintain a sense of humor. Their desire to re-establish a sense of normalcy, even though there were changes in their lives, coincides with Merleau-Ponty's (1945) views related to habituality. The men sought balance through timely establishment of routines, thus contributing to a restoration of the perception of normalcy.

The way that the study participants adapted to the disease also seemed to be in contrast with literature, which addresses the tendency toward depression and loneliness in men who are dealing with chronic illness in general, and especially when dealing with illnesses such as cancer which could be perceived as life-threatening (Alpass & Neville, 2003; Van Servellen, Sarna, Padilla, & Brecht, 1996).
Changes in body image were acknowledged by the men in the study, although the significance of those changes was downplayed. The most significant change that was mentioned was hesitation to swim or remove one's shirt in public. Although some acknowledged that they were personally affected to some extent by a change in body image, there was also concern expressed about how their appearance would be viewed by the public eye. Although it may seem curious that many of the men shared this opinion, it is unknown whether this is reflective of a cultural or regional attitude, as two of the men stated they did not think men their age should be seen in public without a shirt anyway. The fact that the men downplayed the effect of the change in body image does agree with literature, which indicates that the male response to a change in body image will be based on the values and perceptions of each individual (Norris & Spelic, 2002; Timpson, 1999).

According to Merleau-Ponty (1945), the physical body is the avenue through which a person experiences the world. A change in the body, therefore, would have the potential of significantly changing a person's view of self and the world. Since the men in the study stated that the change in their bodies did not have a significant effect, it raises questions. One is left to wonder whether the men were being completely honest with the researcher, and with themselves, when denying that the change in body image had significantly affected them. Perhaps denial of the effect was a protective mechanism, perhaps it was what they perceived to be a societal expectation, or perhaps they were unable to verbalize their true feelings.
It is also possible that the comfort level achieved by the participants during the interview was not enough to allow them to freely discuss their feelings. According to Price (2002), the investigator and the participant need to establish a positive trusting relationship in order for the deepest level of inquiry to produce information related to the participant's values and beliefs. Although each interview seemed to progress quickly to a point where the participant was relaxed and engaged, characteristics of the deepest level of inquiry, it is possible that the level of trust was not as well established as it had seemed at the time.

Some of the participants also stated that their view of time had changed. Some stated that memories had become more precious, or that they felt more sentimental about the past. Some believed that they were slowing down a bit, and that they were unable to accomplish all that they had done in the past. Some identified concerns for the future that were focused on political and financial security. Fear of recurrence of the breast cancer did not play a significant role in the lives of the men in the study.

There is insufficient literature related to male breast cancer patients to compare the findings of this study to time perception and fear of recurrence. There was general agreement among the men, however, that the changes in time perception could have been due, in large part, to the everyday experience of aging. The fact that the participants expressed that their view of time had changed fits well with Merleau-Ponty's (1945) views related to temporality, being drawn away from the present by thoughts of the future. It was impossible,
however, to determine how much, if any, of the change in perception was a result of the breast cancer experience alone.

The third research question asked what effect support of family/friends had on the experience. The study participants in general stated that they found strength and comfort through the support of those who offered support throughout their period of illness and recovery. This is supported in literature, as social support has been identified as the single most important factor in a cancer patient's adjustment (Clark, 1981). Participants denied changes in expressivity, the way that they interacted with others.

The fourth research question asked about the role of one's spiritual/belief system. Study participants who had a strong personal belief system stated that they found it to be a source of strength. Even those who denied having a personal belief system voiced appreciation for those who offered spiritual support to them. Literature confirms that strengthening the spiritual aspect of self will help to build the coping mechanisms needed to deal with a diagnosis of breast cancer (Narayanasamy, 2003; Neuman & Fawcett, 2002). Literature related to spiritual support specific to male breast cancer, however, is lacking.

The fifth research question asked what factors influenced decisions to seek treatment or caused delay in seeking treatment. All of the men in the study stated that they had discovered the indication of breast cancer themselves. Four of the men in the study sought treatment without significant delay. One delayed seeking treatment because he thought the symptoms were insignificant, and one said that he delayed seeking treatment simply because he was a procrastinator.
One of the men who had sought medical treatment did not receive timely intervention because the physician thought the symptoms were insignificant.

The reactions of the men toward seeking help for their symptoms fit well within the Health Belief Model. A cost/benefits analysis of a situation is made, and perceived benefits and barriers are evaluated (Lollis et al., 1995). If going to see the physician is thought to be of high value, one will be motivated to seek medical attention (Dale et al., 1999). The western view of masculinity, associated with strength and self-reliance, may also be a factor in delaying help-seeking. Men may want to conceal vulnerability, thus decreasing their willingness to seek help when first becoming aware of signs of illness (Davies et al., 2000).

In the case of the men in the study, the four men who sought timely treatment perceived that there was a potentially severe situation and that they were potentially vulnerable, even though three of the men did not know that men could get breast cancer. They believed that treatment would be beneficial to the restoration of their health. Their cues to action were the finding of the lump itself, their concern that it was something significant, and, in some cases, the urging of a wife or significant other. In some cases, there were also barriers to seeking help identified, such as being away on a trip, but the perceived severity of the situation, as well as the benefits of being treated, outweighed the barriers and spurred the men to action.

Of the two men who delayed seeking treatment, neither of which knew that men could get breast cancer, one delayed making an appointment at the clinic because of thinking that the symptoms were not severe. The other thought
that the symptoms had the potential of being severe, but did not perceive himself as susceptible to major illness. He therefore delayed seeking treatment, even though his significant other was encouraging him to see a doctor.

An additional theme that arose as a result of the research was related to the need for more information about male breast cancer and treatment options. The study participants, including five men who did not know that men could get breast cancer, indicated that lack of knowledge decreased their ability to make informed decisions. This affected not only their decision to seek treatment, but also the course of treatment that they chose.

The dearth of literature related to male breast cancer is evident, especially when compared with the amount of literature available related to female breast cancer. There is a belief that knowledge about breast cancer in males may always be limited when compared to what has been learned about the disease in females (Jepson & Fentiman, 1998). This will continue to contribute to men having difficulty accessing information, especially when considering that clinical management of males continues to be guided by research on females (O'Malley et al., 2002). This is unfortunate, given the fact that research has shown that breast cancer in males displays a distinctly different evolution and progression, when compared to breast cancer in women (Muir et al., 2003).

Conclusions

Even though the number of male patients diagnosed with breast cancer is small in relation to the female population, further study of male breast cancer is imperative. Although the body of knowledge specific to the area of male breast
cancer is limited, the amount of literature available is slowly increasing. While the majority of the available literature is physiologically-based, it is hopeful that there will be increased research interest related to psychosocial and spiritual issues related to male breast cancer. Based on review of literature, it seems evident that nursing needs to take a lead role in making male breast cancer research a priority, thus contributing to the amount of research-based information available to men and their health care providers.

According to Polit and Hungler (1991), nursing as a profession is accountable for the broadening of a distinct body of knowledge. They address the benefits of new knowledge in this way:

The ultimate goal of any profession is to improve the practice of its members so that the services provided to its clientele will have the greatest impact. Any profession seeking to enhance its professional image undertakes the continual development of a scientific body of knowledge fundamental to its practice. The emergence of such a body of scientific knowledge can be instrumental in fostering a commitment and accountability to the profession’s clientele (p. 3-4).

The development of new knowledge is also addressed by Brink and Wood (1988), who propose that nursing research should be examined in the light of three factors: potential contribution to knowledge, practical value to society, and benefit to the subject. Based on the pressing need for new knowledge in the area of male breast cancer, results of studies such as this one must be disseminated in a way that will maximize the contribution of the study to nursing knowledge, to society, and to the male breast cancer patient, as discussed by Brink and Wood (1988).
Recommendations Related to Research

A primary factor in the absence of information related to male breast cancer in general is the fact that there has been little research done specifically with males. Due to their smaller numbers, research conducted with a large sample of male breast cancer patients would require a vast amount of work and coordination between facilities. Another issue that affects large-scale research is the fact that the clinical management of males continues to be guided primarily by research on females (O'Malley et al., 2002). This may contribute to lack of consistency related to treatment recommendations. It is for this reason that many of the existing studies have been retrospective in nature, and have typically involved patients from only one institution. Comparisons between institutions with differing standards or practices would not produce sound research findings.

Male breast cancer, as previously discussed, is a different disease than its female counterpart and deserves to have its own body of knowledge. Even though the physical aspects of male breast cancer are unique, even more unique is the psychosocial complexity of being a male diagnosed with what may be considered a female disease. It is critical that we learn to understand all aspects of the male breast cancer process, which up to this time has been covered very sparsely in the literature.

Further investigation of male help-seeking behavior is also needed, especially as it relates to breast cancer in men. Until we gain more understanding in this area, it will be difficult to appropriately address the factors that cause delay
in seeking treatment, often resulting in the male patient's breast cancer being in an advanced stage at the time of diagnosis.

Another recommendation for research is to include men who have had a recurrence or metastasis of their breast cancer. Because all of the men in this study reported that they were free of cancer at the time of the interview, their outlook is most likely different from men who have had less positive outcomes.

Lastly, replication of studies such as this, especially in different geographical areas and with men of different cultures, could contribute significantly to nursing's body of knowledge. Efforts to conduct both qualitative and quantitative studies with larger samples are especially needed, with emphasis on psychosocial and spiritual issues.

Recommendations Related to Practice

Another area in nursing's body of knowledge that needs attention is failure to address the lack of public awareness about male breast cancer. As a rule, the general public has little awareness that men could potentially get breast cancer. Even health care providers will admit to lack of knowledge related to male breast cancer (Mouchawar, Klein, & Mullineaux, 2001). It would be anticipated that the most urgent needs of the general public would be increased awareness that men can get breast cancer, as well as specific information related to warning signs, risk factors, occupational exposure risks, and appropriateness of genetic testing. Information about how obesity, inactivity, and alcoholism relate to breast cancer should also be addressed in literature that is available to the general public.
The wife of one of the study participants suggested a “One Blue Ribbon” campaign. She voiced a belief that if one percent of the effort for breast cancer public awareness were directed at males, there would be fewer males who ignore the symptoms of breast cancer, often resulting in negative outcomes. Giving credence to the merits of her suggestion could have positive results through simple acts such as talking about male breast cancer at health fairs, placing ads or short articles in men’s magazines, and speaking publicly about breast cancer at conferences.

Recommendations Related to Education

In addition to putting feet to the campaign for public awareness, recommendations for education must also include undergraduate nursing programs and medical schools. Unless education about male breast cancer is included in the basic education of health care providers such as nurses and physicians, little progress will be made in the areas of early symptom recognition, timely diagnosis, and treatment.

An example of lack of education among health care providers is the case of the one man in the study who sought treatment for his breast lumps. He said that his doctor had been “pushing on those lumps for years.” By the time that biopsy was even considered, his cancer was in an advanced stage, involving 26 of the 27 lymph nodes that were removed. It seems difficult to understand why his physician was not more aggressive. Even harder to understand was the fact that not even one nurse served as an advocate for him or recommended that he
seek a second opinion, even though he reported that he had developed a great rapport with the nurses at the clinic.

There is no indication that there was lack of caring or attention on the part of the health care providers involved in his care. The most logical explanation for the lack of action in his case was that his health care providers were uninformed about the significant consequences associated with the incidence and mortality related to male breast cancer.

In addition to education of nurses and physicians who are involved in their basic educational programs, education of those already in practice is imperative. In order to reach this larger audience, a concentrated effort must be made to provide inservice education and journal articles targeted specifically to the nursing and medical communities. The topic of male breast cancer should also be addressed at local, regional, national, and international conferences.

In order to achieve an optimal level of education for the health care community, it is necessary for health care professionals to rise to the challenge of becoming champions for the cause. Those who become involved in research, practice, and education issues related to male breast cancer will find that doors will open to provide education to their colleagues in many arenas.

Summary

This chapter has presented a summary of the research study, as well as conclusions drawn from the findings of the study. Findings of the study were compared to literature, implications related to the study findings were discussed, and recommendations for research, practice, and education were offered.
It is hoped that this study will contribute toward the furtherance of education related to male breast cancer. Conducting the research involved in this dissertation work has brought to light for the researcher the enormity of the need for further research. It is the hope of the researcher that this work will plant seeds for those who will be future champions in the area of male breast cancer.
APPENDICES
APPENDIX A
Consent Form

You are invited to take part in a research study being done by Marlys Bohn, RN. Marlys is a doctoral student at the University of North Dakota College of Nursing. She is also a teacher at South Dakota State University College of Nursing. Her research is being done under the supervision of her University of North Dakota advisor, Dr. Marcia Gragert.

The purpose of the research is to learn more about how men are affected by experiencing breast cancer. This study will help to provide better understanding of the male breast cancer experience. It will also help members of the health care team to provide the best care possible to male breast cancer patients.

Each man who consents to participate in the study will be interviewed at least once by the researcher. Each interview is expected to last approximately 90 minutes. The interview will be held in a place agreed upon by you and the researcher. The interview will be digitally tape-recorded and then transcribed into text using a computer software program. This will allow the researcher to study the information after the interview. It is possible that a second interview or a follow-up phone call may be needed to clarify information.

It is possible that remembering and discussing issues related to diagnosis and treatment may cause discomfort. If discussion of these issues causes excessive distress, the interview will be stopped and you may be directed to appropriate resources for assistance. There are no other foreseeable risks to you in this study. The benefit which may result from this study is increased understanding of male breast cancer, resulting in improved patient care.

If you choose to participate, you will receive 25 dollars in cash as an appreciation gift for your participation.

All information that you share with the researcher will be kept in confidence. No information from this study that can be identified with you will be disclosed. The only exceptions are issues that require mandatory reporting, such as abuse or threat of injury to self or others. All data and consent forms will be kept in separate locked office cabinets for a minimum of 5 years after the completion of this study. Only the researcher, the adviser, members of the dissertation committee, and people who audit IRB procedures will have access to the data. After 5 years, the identifying data will be shredded.

Results of the study will be included in the researcher’s dissertation. Study results may also be published in health care journals.
Participation in the study is voluntary. Your decision whether or not to participate will not change your future relationship with your health care provider in any way. If you decide to participate, you are free to leave the study at any time without penalty.

If you have questions about the research, you may call Marlys Bohn at 605-688-5736 or Dr. Marcia Gragert at 701-777-4549. If you have any other questions or concerns, please call the University of North Dakota Research Development and Compliance office at 701-777-4279.

I understand that:

1) I will receive a copy of this consent form.

2) I am encouraged to ask any questions that I may have concerning this study now or in the future.

3) A copy of the study results will be provided to me upon request.

4) With my permission, my name and contact information may be kept in a locked cabinet for possible inclusion in future studies.

☐ Yes, you may contact me regarding possible participation in future studies.

☐ No, I would not like to be contacted regarding future studies.

By my signature below, I agree that I have read the above information and that I understand it. All of my questions have been answered at this time, and I agree to participate in the study.

Participant’s Signature ___________________________ Date ____________

Thank you. Please return this consent form in the enclosed postage-paid envelope. You will be contacted by telephone to arrange an interview time.
APPENDIX B
Interview Guide

Answers to the following questions/probes will be sought during the interview process:

1) Please tell me about your experience with breast cancer.
   - How did you learn that you had breast cancer?
   - What factors influenced your decision to seek treatment?
   - If there was a delay in seeking treatment, what were the causes?
   - What were your thoughts/feelings when you were first diagnosed?
   - What type of treatment did you have (surgery, chemotherapy, radiation, hormone therapy)?
     - How did you feel about the different aspects of your treatment?
   - How did your thoughts/feelings change throughout treatment and afterward?

2) How has the experience of breast cancer changed the way that you view your self?

3) How has the diagnosis of breast cancer affected your daily life?
   - Your relationships?
   - Your view of the past, present, and future?
4) Please describe your support system.
   o How has your support system (family/friends/others) affected your experience?
5) What is your religion/spiritual belief system?
   o What role has it had in your breast cancer experience?
6) What has the breast cancer experience meant to you?
   o If you could choose a word to describe the meaning of your breast cancer experience, what would it be? Please explain.

Demographic information:
What is your

• age
• marital status
• personal health history
• family history of breast cancer
• socioeconomic status
• health insurance coverage
• activity level
• disease status
• ethnic group
• education
• employment history
REFERENCES


Clark, E. (1981). The role of social support in adaptation to cancer. The University of North Carolina at Chapel Hill: Chapel Hill, NC.


