Mammography Decision-Making in Women Age 65 or Older With a Family History of Breast Cancer

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ABSTRACT

TITLE: Mammography Decision-Making in Women Age 65 or Older With a Family History of Breast Cancer

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Although much research has focused on factors associated with mammography adherence, few studies have addressed how older women with a breast cancer family history make decisions about whether or not to have mammograms. A convenience, volunteer sample of sixteen Caucasian women ages 67 to 85 with one to three first-degree relatives diagnosed with breast cancer participated in this qualitative grounded theory study. Fourteen were receiving regular mammography screening. Grounded theory methodology was used to generate a theory concerning how older women with a family history of breast cancer make screening mammography decisions. Qualitative data was collected in person using semi-structured interview questions and a demographic questionnaire during one to two interviews.

Being "always on guard for breast cancer", describes the process women went through when making mammography decisions. Women had a heightened awareness of their breast cancer risk and were "always on guard for breast cancer" because it is an ever present threat in their lives. The decision to begin having regular mammograms often began after having a family member diagnosed with breast cancer. A negative mammogram gave women peace of mind and assurance that breast cancer was not

present. Being called back for additional mammograms or other follow up tests often caused worry, anxiety and breast cancer fear, especially when receiving test results was delayed. Women were not receiving adequate clinical breast exams or being referred for genetics services when at risk for a hereditary cancer syndrome. Health care providers need to schedule follow up mammograms as soon as possible, minimize the time it takes to report test results, provide a complete annual clinical breast exam, obtain a family history of cancer, and refer women with a strong family history of cancer for genetic services.

Future research needs to examine the negative emotional consequences of abnormal mammograms such as worry, anxiety, and cancer fear and test interventions such as providing same day follow up tests, shortening the time to it takes for a woman to receive test results, and providing emotional support.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

Introduction

Nearly half of all breast cancer diagnoses and more than half of breast cancer deaths occur among women over the age of 65 (American Geriatrics Society [AGS], 1999). In addition, women age 65 and older with one first-degree relative diagnosed with breast cancer have a 40 to 50 percent higher risk of being diagnosed with the disease, compared to women without this family history. This risk persists even when breast cancer is diagnosed in the first-degree relative after age 65 (Colditz, 1993; Colditz & Rosner, 2000). If an older women has both a mother and sister diagnosed with breast cancer, her breast cancer risk is two and a half times that of a woman the same age without that family history (Colditz, 1993). In these high risk older women, breast cancer surveillance is especially important.

In spite known mammography benefits and Medicare coverage for mammograms, a study of 10,000 women age 65 and older found 60 percent of these women had either not undergone screening mammography or had received only one mammogram in the past five years (Harrison et al., 2003). Only about half of women older than age 50, and even fewer older than age 70, undergo mammography in accordance with American Cancer Society guidelines (Roetzheim, Fox, Leake, & Houn, 1996). In older women with a family history of breast cancer, 25% to 35% had not had a screening mammogram in the previous 2 years and as many as 20% and higher reported never having had a mammogram in their lives (Lerman et al., 1993; Roetzheim et al., 1996).

In women age 50 and older, mammography is currently the most effective method for detecting breast cancer at an early stage when cure is most likely. Six randomized trials looking at mammography screening in women over age 50 showed a 30 to 50 percent reduction in mortality (Andersson et al., 1988; Frisell, Lidbrink, Hellstrom, & Rutqvist, 1997; Miller, To, Baines, & Wall, 1997; Roberts et al., 1990; Tabar et al., 1985). Several meta-analyses of these and other trials concur that mammography reduces breast cancer mortality in older women (Allweis et al., 2003; de Koning, 2003; United States, 2002; Hackshaw, 2003; Kerlikowske, Grady, Rubin, Sandrock, & Ernster, 1995; Nystrom et al., 2002; Tabar et al., 2002). Women age 65 and older who undergo mammography are more likely to be diagnosed with early stage breast cancer, less likely to develop metastatic disease, and less likely to die of breast cancer compared to women who do not undergo mammography (Kerlikowske et al., 1995; McCarthy et al., 2000; Smith-Bindman, Kerlikowske, Gebretsadik, & Newman, 2000; Tabar et al., 2001). In addition, using a decision analysis model, mammography screening increased Quality Adjusted Life Years in women age 75 and older with and without cognitive impairment (Messecar, 2000).

In a randomized trial of over 600,000 women aged 66-79, women who had mammography were more likely to be diagnosed with early stage breast cancer and 43% less likely to develop metastatic disease compared to women diagnosed with breast cancer who had not undergone mammography (Smith-Bindman et al., 2000). In a similar study of 11,399 women aged 67 and older, women who received mammography were significantly less likely to die of breast cancer and more likely to be diagnosed at “Stage 1” for the disease. These benefits of mammography were found to be significant until age 85 (McCarthy et al., 2000).

Both increased age and having a family history of breast cancer are associated with an increased likelihood that an abnormal mammogram will result in a breast cancer diagnosis versus a benign finding (Kerlikowske et al., 1993). Since older women with a family history of breast cancer are at increased breast cancer risk due to both age and family history and because an abnormal mammogram is more likely to result in a cancer diagnosis, the number of these high risk women who do not undergo regular mammography screening is a health care problem that is not well understood. In spite of considerable research related to mammography utilization patterns, factors associated with increased or decreased mammography use, and interventions to increase mammography utilization, there are still a significant number of older women who do not undergo regular mammography screening (Breen, Fewer, Depuy, & Zapka, 1997; Brenes & Skinner, 1999; Burns et al., 1996; Fletcher et al., 1993; Rawl, Champion, Menon, & Foster, 2000; Saywell et al., 1999). Studies that do include older women often do not separate out women over age 65 from younger women in the findings, do not include women over 69 in the sample, or do not address whether a family history of cancer is present (Cooper et al., 1998; Fletcher et al., 1993; Saywell et al., 1999; Van Harrison et al., 2003). In order to improve mammography utilization rates in older women with a family history of breast cancer we need information concerning how they make decisions about whether or not to have a mammogram.

Background

Invasive breast cancer is estimated to affect 211,240 women in the USA in 2005, and 55% of these women will be age 60 or older. Since 1986, breast cancer incidence has increased only in women age 50 and older. In addition, 40,870 women in the USA are expected to die of breast cancer in 2005 and 68% of these women will be age 60 or older (American Cancer Society [ACS], 2005). In Oregon, 1,320 women age 60 or older were diagnosed with invasive breast cancer and 340 died from the disease in 2001, which is the most recent report available (Sherman-Seitz & Pliska, 2004). For the first time cancer has outstripped heart disease as the leading cause of death in those age 84 and younger, and is the second leading cause of death in those 85 and older (ACS, 2005). About seven percent of all breast cancer diagnoses are attributable to having a first-degree relative diagnosed with the disease (Colditz, Rosner, & Speizer, 1996; Hemminki, Granstrom, & Czene, 2002; Pelucchi, Negri, Tavani, Franceschi, & La Vecchia, 2002). The attributable risk could be closer to 11% if both the maternal and paternal family history were included in the risk assessment (Hemminki et al., 2002). According to a large meta-analysis, women with one or more first-degree relatives diagnosed with breast cancer are about one and a half to two times more likely to be diagnosed with the disease and are more likely to develop breast cancer in middle or old age (Collaborative Group on Hormonal Factors in Breast Cancer [CASH], 2001). Women with a family history of breast cancer who have abnormal mammograms are more likely to have breast cancer compared to women with negative mammograms and a negative family history of breast cancer (Kerlikowske et al., 1993). Interval cancer rates were found to be higher and tumors were larger in women with a family history of breast cancer compared to women without this history in a large randomized trial comparing the efficacy of mammography screening in women with and without a family history of breast cancer. The authors interpreted these findings to mean that annual mammography screening may be necessary for women with a positive family history, which is consistent with current American Cancer Society guidelines (Nixon et al., 2000; Smith, Cokkinides, & Eyre, 2005).

Although a lot has been written about mammography screening, few studies have addressed how women make decisions concerning whether or not to have a mammogram. Most of the articles concerning breast cancer decision making have focused on breast cancer treatment options. Few articles were found that addressed some aspect of the decision making process women go through in making breast cancer surveillance decisions.

Knowledge concerning the processes older women with a family history of breast cancer go through when making decisions concerning screening mammography can guide future research aimed at increasing mammography screening. It can also sensitize health care providers to factors that influence screening mammography decision making and facilitate higher breast cancer screening rates for older women with a family history of breast cancer.

Statement of the Problem

Since mammography reduces the risk of breast cancer mortality in older women, the proportion of older women who are not receiving regular mammography is a health care problem that needs to be addressed. Further improvement in mammography utilization rates is essential if we are to meet the Healthy People 2010 goal of a 20% reduction in breast cancer deaths in the next nine years (Healthy People 2010, 2001 accessed December 5, 2003 at http://www.health.gov/healthypeople). Despite mammography being associated with a fewer breast cancer deaths and finding new cases of breast cancer earlier, rates of use are lower than expected especially in older women, with as many as 40% having not undergone screening in the previous five years (Cooper et al., 1998).

Although a significant amount of research has focused on factors associated with whether or not women receive mammography screening, few studies have addressed how women make decisions concerning whether or not to have a mammogram. One study found that women at high risk for breast cancer wanted guidance in breast cancer decision making, including information about risk breast cancer risk factors, screening recommendations, lifestyle options, and breast cancer prevention (Stacey, DeGrasse, & Johnston, 2002). According to Lewis et al. (1999), most researchers have focused on factors associated with women's behavior related to breast cancer screening, rather than on the decision making that preceded the behavior. This study attempts to help fill that gap.

Women age 65 and older with a family history of breast cancer were chosen as the study population for several reasons. Although women age 65 and older comprise only about 14 percent of the population, nearly half of breast cancer cases and more than half of breast cancer mortality occurs in this age group (Smith-Bindman et al., 2000). The absolute risk for breast cancer is greater in older women with a family history of the disease compared to those without (CASH, 2001) and older women are less likely to undergo screening mammography compared to younger women (Lane, Zapka, Breen, Messina, & Fotheringham, 2000; Miller & Champion, 1996). In addition, older women who receive mammography are less likely to die of breast cancer and more likely to be diagnosed at an early disease stage compared to younger women.

Significance to Nursing

Breast cancer is a health problem that has great significance to all women, their families and health care providers. Mammography studies have found that health care providers can make a difference in terms of interventions that increase mammography screening. Telephone and in person counseling increased screening mammography in women ages 50 to 85 (Champion, Skinner, & Foster, 2000). Nurses have long been involved in health education and screening and nurse researchers are in an ideal position to conduct studies aimed at better understanding how older women with a family history of breast cancer make decisions regarding mammography screening. Although issues related to mammography screening are relevant to all women and the health care providers who care for them, nurses represent the largest body of health care providers caring for women at risk for breast cancer who may benefit from mammography screening. This presents an excellent opportunity for nurse researchers to be on the forefront in exploring issues related to mammography decision making in older women. Hopefully the information gained from the present study will help health care providers better care for, support, and communicate with older women with a family history of breast cancer regarding breast cancer screening. Findings from the present study will guide future research related to breast cancer screening decision making as well as help inform studies aimed at increasing mammography in older women with a family history of breast cancer.

Study Purpose and Aims

The purpose of the present study is to generate a beginning grounded theory concerning how older women with a family history of breast cancer make screening mammography decisions, and identify conditions, context, and meanings, that influence screening mammography decision making processes in these women. Using grounded theory, a semi-structured interview process will be used. Study aims include the following:

1. Identify antecedent, concurrent, and consequent factors associated with the process of mammography decision making in older women with a family history of breast cancer.
2. Describe the conditions, context, and meanings influencing screening mammography decision making in older women with a family history of breast cancer.
3. Identify strategies that promote mammography in older women with a family history of breast cancer.
4. Generate an initial grounded theory of screening mammography decision making processes in older women with a family history of breast cancer.

CHAPTER TWO

Review of the Literature

This chapter will present relevant background literature related to breast cancer risk, mammography screening, and breast cancer decision making. The first section on breast cancer risk includes an overview of breast cancer risk factors, breast cancer risk associated with age and family history of breast cancer, and hereditary breast cancer risk. The second section on mammography screening summarizes studies looking at mammography screening in all older women, mammography screening in older women with a family history of breast cancer, factors associated with increased or decreased mammography adherence, interventions aimed at increased mammography screening, and mammography screening recommendations for women age 65 and older. The third section summarizes selected areas of the decision making literature including breast cancer decision making, breast cancer treatment decision making, decision making in older versus younger women, breast cancer surveillance decision making, and several decision making models. This literature is then summarized and gaps in the literature identified.

Breast Cancer Risk Factors

Age, Family History, and Breast Cancer Risk

Both increased age and having a family history of breast cancer are significant risk factors for the disease. Although breast cancer is uncommon under age 40, the incidence goes up dramatically with increased age. By the time a woman has reached age 70, her breast cancer risk is 18 times higher than it was at age 40 (ACS, 2005). Breast cancer incidence continues to go up as age increases (Edwards et al., 2002). Family history of breast cancer also increases risk. In the Nurses Health Study, unaffected women with a mother or sister diagnosed with breast cancer were at least 46 percent more likely to be diagnosed with the disease in this longitudinal study, although this data is based on limited numbers and age of breast cancer diagnosis was not included (Colditz & Rosner, 2000). Women with both a mother and sister diagnosed with breast cancer have a relative risk of 2.5 compared to women without a family history of the disease (Colditz et al., 1996). In a large, case controlled study, women diagnosed with breast cancer with a mother or sister diagnosed with the disease had a relative risk of 2.4 compared to women diagnosed with breast cancer without a breast cancer family history, regardless of age at diagnosis (Negri, Braga, La Vecchia, Franceschi, & Parazzini, 1997).

Reproductive, Hormonal, and Other Breast Cancer Risk Factors

Data from the Nurses Health Study showed that reproductive breast cancer risk factors for women without a family history of breast cancer included age at menarche, age at first birth, age at subsequent births, and age at menopause (Rosner, Colditz, & Willett, 1994). Women with a family history of breast cancer, however, showed little protection from later age at menarche, no protection from multiple births or early age at first birth, no increased risk from late menopause, and a 50 percent greater increase in breast cancer risk from first pregnancy compared to women without a family history (Colditz et al., 1996; Colditz et al., 1993). Obesity after menopause increased breast cancer risk about 20 percent. Postmenopausal unopposed estrogen use was associated with an increased breast cancer risk up to 23 percent with 10 years of use, and taking progestin in addition to estrogen more than doubled this risk. Women with and without a breast cancer family history who reported a diagnosis of benign breast disease or fibrocystic breast disease had about a 57 percent increase in breast cancer risk. A breast biopsy showing atypical hyperplasia was associated with a four fold increase in breast cancer risk (Colditz, 1993; Colditz & Rosner, 2000). A limitation of the Nurses Health Study is that breast cancer risk was specified only up to age 70. Both alcohol and tobacco have been associated with increased breast cancer risk, although the effect is small (Hamajima et al., 2002).

Hereditary Breast Cancer Risk Factors

About 5 to 10 percent of breast cancers are related to inherited cancer predisposing genetic alterations (Frank & Braverman, 1999). The majority of hereditary breast cancer (about 84%) is now thought to be related to alterations in two genes, *BRCA1* and *BRCA2* (Frank et al., 1998). Everyone has two copies of *BRCA1* and *BRCA2*, one copy of each inherited from each of their parents. *BRCA1* stands for "breast cancer one" because it was the first gene associated with hereditary breast cancer to be identified. *BRCA1* is located on chromosome 17 and was first identified in 1994. *BRCA2* is located on chromosome 13 and was identified in 1995. Both of these genes are autosomal dominant, which means that a person with either a *BRCA1* or *BRCA2* alteration has a 50% chance of passing on the same alteration to one of their children. When these genes are functioning properly, they act as tumor suppressor genes (Fearon, 1997). A copy that has been damaged is not able to suppress cellular changes that lead to cancer. If a child inherits two normal copies of these genes, then their breast cancer risk will be similar to that of the general population. If, however, one altered copy and one normal copy of either *BRCA1* or *BRCA2* is inherited, a woman will have a breast cancer risk of about five to six times that of the general population (56% to 87% compared to 12%). These genes are also associated with increased risk for other cancers in addition to breast cancer. *BRCA1* is also associated with about a 28-44% risk of ovarian cancer (compared to 1-2%

in the general population), and an increased risk for colon and prostate cancers. *BRCA2* is associated with about a 27% risk for ovarian cancer and increased risk for male breast cancer, prostate, and pancreatic cancer (Frank et al., 2002; Frank et al., 1998). Because of the high risk for both breast and ovarian cancer in women known to carry a *BRCA1* or *BRCA2* mutation, it is sometimes referred to as breast ovarian cancer syndrome.

In addition, there are several less common genetic alterations associated with cancer syndromes that also include breast cancer (Lindor & Greene, 1998). Whether or not a person carries a cancer predisposing mutation has clinical significance for cancer screening. Cancer screening guidelines for breast cancer are stratified according to level of risk (ACS, 2005; Smith et al., 2005). For example, current evidence suggests that high risk women familial or genetic predisposition to breast cancer should be screened with magnetic resonance imaging instead of mammography (Kriege et al., 2004).

Breast Cancer Risk Perception and Psychosocial Factors

Much of the research to date on women with a family history of breast cancer has focused on perception of breast cancer risk in younger women. One grounded theory study explored and described the meaning of the risk experience in 55 women (ages 20-69) with a family history of breast cancer (Chalmers & Thomson, 1996). A personal view of risk occurred in three phases: living the breast cancer experience of the relative(s), developing a risk perception, and putting risk in its place. “Adopting self-care practices” tended to occur as the final process of “putting risk in its place”. Whether or not age affected the risk experience was not reported. In two studies conducted in London, women with a family history of breast cancer receiving genetic counseling for breast cancer risk showed no decrease in anxiety and continued to overrate their own breast cancer risk (Lloyd et al., 1996; Watson et al., 1999). In another study, having a family history of breast cancer had little impact on a woman's perception of breast cancer risk with all women significantly overestimating their risk and increased age was associated with increased breast cancer risk perception (B. L. Smith et al., 1996). In a study of 335 women (ages 37 to 77) perceived susceptibility to breast cancer was positively related to family history and breast symptomatology. In addition, women believed early mammography screening would lead to lower breast cancer risk at a later time (Aiken, Fenaughty, West, Johnson, & Luckett, 1995).

In a qualitative study of breast cancer risk and mammography, women recognized the importance of breast cancer risk factors such as age, family history, and genetics, however, they gave equal importance to factors such as smoking, diet, toxic exposures, and bad attitudes with little or no link to breast cancer. The authors concluded that the exaggerated importance many women attributed to modifying controllable risk factors could lead women diagnosed with breast cancer to blame themselves. Women believed that even benign breast abnormalities had the potential to become cancerous and viewed breast cancer as a uniformly progressive disease rarely curable unless caught early (Silverman et al., 2001).

Many women, especially if they have a family history of breast cancer, overestimate their personal breast cancer risk. They may continue to be anxious and overrate their breast cancer risk even after receiving cancer risk counseling, especially if they are anxious before counseling. Although some studies include older women over age 65, this age group is poorly represented in these studies and findings related to this age group are rarely separated out (Chalmers & Thomson, 1996; Kash, Holland, Halper, &

Miller, 1992; Lerman, Kash, & Stefanek, 1994). Whether or not older women responded differently than younger women was not reported.

Risk Perception and Breast Cancer Screening Behaviors

Studies looking at the association between risk perception and breast cancer screening behavior have been inconsistent. Findings from six of seven studies reviewed by McCaul et al. (1996) showed that women reporting higher perceived breast cancer risk were more likely to receive mammography. Possible explanations for these findings include: increased provider recommendations for mammography due to a greater number of breast cancer risk factors; women who feel vulnerable may be more motivated to have mammography; or mammography screening could cause women to have increased vulnerability and worry.

Other studies have not found perceived risk to increase screening. In two studies of women with a family history of breast cancer, although most women knew their breast cancer risk was increased, this was not associated with increased mammography screening (Drossaert, Boer, & Seydel, 1996; Vogel et al., 1990). Women receiving 20 minutes of counseling by a surgeon had a more accurate perception of breast cancer risk and lower anxiety compared to women receiving a newsletter, however, there was no significant change in BSE frequency in either group (Gagnon et al., 1996). In a study of high risk women under age 50, psychological distress was associated with non-adherence to mammography and with infrequent and excessive breast self examination (Lerman et al., 1994). Another study found that individual breast cancer risk counseling decreased mammography use among less educated women at risk for breast cancer (Schwartz, Rimer, Daly, Sands, & Lerman, 1999). It is possible that breast cancer risk counseling lowers perception of breast cancer risk and this may lead to decreased screening behavior.

Mammography Screening

In addition to having a family history of breast cancer, a number of other factors have been associated with increased or decreased use of screening mammography in older women. Mammography research has primarily focused on factors associated with increased or decreased use of screening mammography.

Mammography Screening in Older Women

The implementation of Medicare reimbursement for mammograms in 1991 was anticipated to significantly increase mammography use among women over age 65. However, this increase has been much lower than expected (Preston et al., 1997). In one study looking at women eligible for Medicare mammography reimbursement, utilization only increased from 14.6% to 17.4 % in the first two years after reimbursement was implemented (Breen et al., 1997).

In a study comparing breast cancer screening practices of older and younger women, 67% of women age 75 and older, and 64% of women ages 65 to 74 had never had mammography, compared to only 59% of women ages 55 to 64. Only 14% of women in both the 65 to 74 and 75+ age groups reported having two or more mammograms, compared to 19% of women ages 55 to 64. In addition, fewer women age 65 and older reported having had a clinical breast exam compared to women ages 55 to 64 (Halabi, Vogel, Bondy, & Vernon, 1993). In a study of 2,352 women age 75 and over, only 26.7% had received a mammogram in the past two years (Blustein & Weiss, 1998).

Adherence to Mammography Screening Recommendations

Adherence and compliance are two terms found in the literature when referring to whether or not women adhere to mammography screening guidelines. In reviewing the literature concerning mammography adherence, there does not appear to be a standard method used by researchers for defining mammography adherence. The time frames most often used in studies looking at mammography adherence are one year, 15 months , two years, two years and three months, or three years. (V. L. Champion, 1999; V. L. Champion, Skinner et al., 2000; Crane et al., 1998; Diefenbach, Miller, & Daly, 1999; Duijm, Guit, & Zaat, 1997; D. Lauver, Nabholz, Scott, & Tak, 1997; Lerman et al., 1993; A. M. Miller & Champion, 1993; Sadler et al., 2001; Veit, 1999) The rationale for the additional three month time period is to give women a time period to receive a mammogram after they were due.

Mammography screening recommendations are not entirely consistent, especially in women over age 75. The American Geriatrics Society recommends annual or biennial mammography until age 75, and biennial screening or at least screening every three years for women over age 75 with a life expectancy of four years or more (AGS, 1999). The American Cancer Society recommends annual mammography starting at age 40, with no upper age limit (R. A. Smith et al., 2005). Both the National Cancer Institute and the United States Preventative Health Services Task Force recommend mammography screening every one to two years starting at age 50 with no upper age limit (National Cancer Institute, 2002). Despite recommendations by these professional organizations for regular mammography screening, only a small percentage of older women are receiving regular screening mammography according to recommended guidelines (Harrison et al., 2003; Roetzheim et al., 1996). Even when health care providers recommended mammograms to women ages 60 and older, only one third followed through with the recommendation (Blair, 1998).

Mammography in Older Women With a Family History of Breast Cancer

Although many studies do not address "family history of breast cancer", it usually refers to having at least one first-degree relative with a breast cancer diagnosis (Bastani, Maxwell, Bradford, Das, & Yan, 1999; Cancer, 2001; Chalmers, Thomson, & Degner, 1996; Kash et al., 1992; D. R. Lauver, Kane, Bodden, McNeel, & Smith, 1999). Mammography is especially important in older women with a family history of breast cancer. Not only are these women at increased risk for breast cancer due both to their age and their family history, (Cancer) but mammography in this group of women is more likely to indicate that cancer is present (Kerlikowske et al., 1993). Because breast tissue has a higher fat composition in women over age 50, mammograms are easier to read and more sensitive than in younger women (Kerlikowske, Grady, Barclay, Sickles, & Ernster, 1996). Breast cancer in women with a family history of breast cancer is also more likely to be detected by mammography at an earlier stage (Tilanus-Linthorst, Bartels, Obdeijn, & Oudkerk, 2000). Mammography screening provides the primary means of reducing breast cancer mortality, although clinical breast exam has also been found to contribute to reduced breast cancer mortality rates (McDonald, Saslow, & Alciati, 2004; Saslow et al., 2004; Senie, Lesser, Kinne, & Rosen, 1994).

Mammography utilization in women with a family history of breast cancer

In spite of higher mammography screening rates for women with a positive family history, a substantial proportion of these women still receive infrequent mammography screening or have never been screened (Roetzheim et al., 1996). A meta-analysis of 19 studies comparing the mammography screening behaviors of women with and without a family history of breast cancer found that women with a family history were more likely to have been screened (McCaul, Branstetter, Schroeder, & Glasgow, 1996). Findings from other studies not included in the meta-analysis support the finding that women with a family history of breast cancer are more likely to undergo screening mammography (Hawley, Earp, O'Malley, & Ricketts, 2000; Lane et al., 2000; Roetzheim et al., 1996; Segura, Castells, Casamitjana, Macia, & Ferrer, 2000). The authors point out, however, that providers may recommend mammography more often to women who have a family history of breast cancer.

Number of relatives with breast cancer has also been linked to mammography screening. Women over age 35 with two or more first-degree relatives were over twice as likely to adhere to mammography screening as women with one affected first-degree relative (Schildkraut, Lerman, Lustbader, & Rimer, 1995). Several early studies, however, failed to find a relationship between family history of breast cancer and mammography use (Costanza, Stoddard, Gaw, & Zapka, 1992; Lerman et al., 1993; Roetzheim et al., 1996; Vogel et al., 1990). In a recent study, women with a family history of breast cancer were more likely to undergo mammography screening compared to women without this history, and increased age was correlated with decreased screening regardless of family history (Murabito et al., 2001). An earlier, similar study found older women had lower mammography utilization rates compared to younger women and having a family history of breast cancer did not influence mammography screening rates, even when the women knew age and family history increased breast cancer risk (Costanza et al., 1992).

In spite of evidence that women with a family history of breast cancer undergo more frequent mammography screening, mammography utilization rates for older women in this population are still low. According to a study of over 5,000 women at five National Cancer Institute Breast Cancer Screening Consortium sites, only 46 to 61% of Medicare-insured older women with a family history of breast cancer had received mammograms in the past year. At some sites more than 20% of these high risk older women reported never having had a mammogram (Roetzheim et al., 1996). These findings are supported in another study of 140 women age 35 to 79 with a first-degree relative with breast cancer (Lerman et al., 1993). In women age 50 and older, only 63% had received annual mammograms and 13% had never had a mammogram.

Health Care Provider Factors Related to Mammography Utilization

The most powerful predictor positively associated with mammography utilization is health care provider recommendation. Numerous studies have found that women were more likely to have mammograms if their provider recommends them (Champion, 1992; Costanza et al., 1992; Hawley et al., 2000; Lane et al., 2000; A. M. Miller & Champion, 1993; Resnick, 2000). In one study women age 50 and older were 14 times more likely to have had a mammogram if their provider recommended it than when their provider did not recommend the test (A. M. Miller & Champion, 1996). Having a health care provider and making regular visits to a physician have both have been associated with increased mammography utilization. Whether or not health care providers recommended mammography to women at these visits is not reported (Bush & Langer, 1998; Segura et al., 2000). Women were twice as likely to undergo mammography screening if they saw a female, rather than a male, physician (Andersen & Urban, 1997). It is interesting to note that all but two of these studies looked only at physician health care providers. Bush and Langer (1998) used the term "medical provider" and Resnick (2000) referred to "health care provider".

Of 234 women age 35 years or older with a first-degree family history of breast cancer, 47% had not received mammography within two years. General practitioners of women not receiving mammography were surveyed and 70.3% identified provider related barriers such as lack of physician recommendation due to insufficient retrieval system or disagreement with mammography guidelines. For the remaining 29.7%, women were contacted and identified patient related barriers such as lack of perceived need due to not having breast symptoms. Nearly half of the women who identified provider related barriers underwent mammography after a reminder was received (Duijm et al., 1997). Another study looked at patient factors that influenced whether or not physicians recommended mammography (Marwill, Freund, & Barry, 1996). The variables of age older than 75, mild dementia, and nursing home residence were all independently associated with physicians being less likely to recommend mammography. The presence of chronic medical problems or functional limitations, however, did not have an impact on mammography recommendation. According to the authors, study results imply that physicians may determine breast cancer screening practices based on age rather than using life expectancy based on comorbidity.

An important contextual factor to consider is that mammography requires a health care provider to order and interpret the results. Even when women self refer for mammography it requires a physician for interpretation, unlike smoking cessation and exercise which can be pursued without health care provider involvement (Rakowski et al., 1992).

History of Breast Problems and Mammography Utilization

History of breast problems was associated with increased mammography utilization in nine out of ten studies in a meta-analysis (McCaul et al., 1996). The authors point out, however, that although it appears that having a history of breast problems may increase mammography utilization, it is also possible the women may simply have discovered breast problems through mammography. Findings from several other studies, completed after the meta-analysis was reported, supported the finding that a history of breast problems was associated with increased mammography use (D. R. Lauver et al., 1999; Roetzheim et al., 1996; Segura et al., 2000). Miller and Champion (1993) found women with a history of benign breast disease were four times more likely to adhere to mammography screening guidelines compared to women without benign breast disease.

Health Insurance, Education, Income, and Ethnicity

Having health insurance has been associated with increased mammography screening. In women age 65 and older having Medicare without supplemental insurance or having Medicaid with Medicare is associated with a lower likelihood of having a mammogram (Bush & Langer, 1998; Lane et al., 2000; Lee & Vogel, 1995; A. M. Miller, 1994).

Higher education and higher income have both been associated with increased mammography screening. It is not surprising that both factors are jointly associated with increased mammography screening, since education and income are often related (Bush &

Langer, 1998; Lane et al., 2000; Lee & Vogel, 1995; A. M. Miller, 1994; Segura et al., 2000).

Ethnicity has not consistently been found to be a factor. In two studies that specifically looked at ethnicity and mammography utilization, no significant differences were found (Bush & Langer, 1998; Thomas, Fox, Leake, & Roetzheim, 1996). However, being African-American or Hispanic was associated with lower mammography utilization in three studies (Lee & Vogel, 1995; A. M. Miller, 1994; Rawl et al., 2000).

Age of the Woman and Health Screening Practices

Women age 60 and older have been consistently less likely to undergo screening mammography compared to younger women (Hawley et al., 2000; Lane et al., 2000; D. Lauver et al., 1997; Lee & Vogel, 1995; Rawl et al., 2000; Taplin, Anderman, & Grothaus, 1989). Age has been found to be inversely related to mammography screening (A. M. Miller & Champion, 1993).

The "habit of seeking preventive care" is associated with increased use of mammography screening (D. Lauver et al., 1997). This is consistent with the finding that practicing breast self-exam, receiving a pap smear and receiving clinical breast exam have all been associated with increased use of mammography screening (Roetzheim et al., 1996; Segura et al., 2000). Women having annual Pap tests are much more likely to follow mammography guidelines compared to women not having Pap tests (A. M. Miller & Champion, 1996).

Intervention Studies Aimed at Increasing Mammography Use in Older Women

Intervention studies have tested several approaches aimed at motivating women to have regular mammograms. Interventions associated with increased mammography use in older women include: physician education, provider prompts, patient education materials, transportation assistance, and appointment scheduling assistance. When all of these interventions were implemented, screening mammography increased from 22 % to 49 % in a study of 314 women (ages 50 to74) (Taylor et al., 1999). This finding is consistent with a similar study where patient education, appointment assistance, and transportation assistance increased screening mammography among women in senior citizens' housing facilities (E. King et al., 1998). Telephone and in person counseling were both effective in increasing mammography adherence in 1,098 women (ages 50 to 85) (Champion, Skinner et al., 2000). A similar study found that a phone prompt and physician reminder was effective and economical in increasing screening mammography (Saywell et al., 1999).

A study that involved sending individual mailings containing information about breast cancer risk and community sources for screening, and providing information and screening at local county fairs to 1545 rural women found significant changes in knowledge and attitudes about breast cancer and increased use of screening mammography in the intervention group (Gardiner, Mullan, Rosenman, Zhu, & Swanson, 1995). In another study, a computer tracking system reminding providers mammograms were due improved utilization in a study of low-income women (Paskett et al., 1998).

The effect of Medicare reimbursement combined with interventions promoting mammography use is also of interest. In a study of over 6,000 women (ages 65 to 74), women were interviewed regarding mammography utilization over a two year period at six intervention and five control sites. This was done in 1991, the first year Medicare reimbursement for mammograms was implemented, and again two years later. Interventions consisted of physician and patient reminder systems, and community based education programs. The data at all sites showed little overall increase in mammography utilization between 1991 and 1993. However, Medicare payment for mammography was significantly higher at the intervention sites than at the control sites. The authors concluded that implementation of Medicare reimbursement alone was insufficient to significantly increase utilization without additional interventions (Breen et al., 1997).

The impact of receiving personalized information about breast cancer risk factors on mammography use was the focus of anther study. A survey was sent out to 900 women with at least one first-degree relative with breast cancer to gather breast cancer risk information. A letter with a description of the woman's breast cancer risk factors, an estimation of breast cancer risk, and an education booklet was mailed to half the women with the other half receiving information on breast cancer and mammography. There was no effect among women under age 50, however, women age 50 and older were 20% more likely to receive mammography after the intervention (Bastani et al., 1999).

In summary, a number of interventions have been effective in improving mammography utilization. These include: physician education, provider prompts, patient education materials, patient reminders, transportation assistance, and appointment scheduling assistance. Although health care provider recommendation has consistently been shown to improve mammography utilization, many women do not follow through the recommendation (Blair, 1998). Most mammography studies have focused on factors associated with mammography utilization, and a few have looked at interventions. Perhaps this is because correlational utilization studies can be done more easily since large databases can be used (Hawley et al., 2000).

Decision making

Decision making is a broad construct that has been the subject of numerous research studies related to breast cancer. The broad variety of theoretical frameworks and how they can be used in breast cancer decision making is not always understood.

Decision Making Studies Related to Breast Cancer Treatment

Much of the breast cancer decision making literature has focused on women facing a decision about breast cancer treatment and how much control they want to have in the decision making process. These studies have generally found that women facing treatment decisions want their physician to have greater control in treatment decision making with older women wanting less input in decision making than younger women. (Beaver et al., 1996; Hack, Degner, & Dyck, 1994; Petrisek, Laliberte, Allen, & Mor, 1997). In addition, decision making and information seeking do not appear to be linked (Ende, Lewis, Ash, & Moskowitz, 1989).

A study of oncologists, oncology nurse practitioners, oncology nurses and women diagnosed with breast cancer found that oncology nurses and nurse practitioners felt patients should have more input in medical decision making than either patients or physicians thought they should have. All groups believed physicians should have the dominant role in decision making (Beisecker, Helmig, Graham, & Moore, 1994).

Other studies looked at preferred and actual roles in treatment decision making among women with newly diagnosed breast cancer. Only about half of women surveyed actually achieved their desired level of participation in treatment decision making (Degner et al., 1997; Keating, Guadagnoli, Landrum, Borbas, & Weeks, 2002). In Bilodeau and Degner's (1996) study, although 37% of women preferred a collaborative decision making role, only 19% were able to assume such a role indicating that women who want collaborative roles may experience difficulty in achieving them. Women were more likely to both prefer and assume a passive role in treatment decision making, especially older women (Bilodeau & Degner, 1996).

In a study looking at decisional preferences in 1,012 women with breast cancer, women with a family history of breast cancer rated information about family risk more important than other women regardless of age. In addition, women older than 70 were much less likely to prefer an active role in decision making and more likely to want information about self-care (Degner et al., 1997). In a study of 76 women newly diagnosed with breast cancer using a median split, women age 52 and younger were more likely to want the physician to make the treatment decisions, while women older than 52 were more likely to want to make treatment choices themselves (Johnson et al., 1996). In a different study of 150 women newly diagnosed with breast cancer and 200 women with benign breast disease, most women preferred to have the physician make treatment decisions. There was a weak correlation with older age and lower socioeconomic class being associated with a more passive decision making role (Beaver et al., 1996).

Persons without a cancer diagnosis are more likely to want involvement in health care decision making than those diagnosed with cancer (Degner & Sloan, 1992). Whether or not this applies to women without a cancer diagnosis is unknown. Decision making studies rarely addressed whether or not women had a family history of breast cancer.

Decision Making and Breast Cancer Surveillance

Little is known about how women make decisions concerning breast cancer surveillance and how health professionals can help them in the decision making process. In one study 50 women (ages 36 to 83) were interviewed regarding how they made decisions about screening mammography (Lewis, Corcoran-Perry, Narayan, & Lally, 1999). Three approaches to decision making were identified. The "thoughtful consideration approach" was used by 21 women, 12 of whom chose to have mammography. These women considered factors such as age, family history, breast cancer risk factors, reliability of mammography, risks and benefits of the test, personal experience, and practical considerations such as time and transportation when arriving at a decision. Of the 10 women who used the "cursory consideration approach", where some factors were taken into account in the decision, six women chose to have mammography. The "little or no consideration approach was used by 13 women, 12 of whom had mammography. These women showed minimal or no evidence of using information in making a decision about mammography and identified someone else as making the decision, most often the physician. This study is interesting in that it appears that the more women considered the decision, the less likely they were to have a mammogram. Differences due to family history and age were not included.

In a large study of women age 50 to 75 in an HMO, the decision to obtain mammography was related to giving and receiving health-related information with other women (Pearlman, Rakowski, & Ehrich, 1995). Another study of 41 women (ages 27 to 84), 12 of whom had a family history of breast cancer, looked women's views about breast cancer, their personal risk of breast cancer, and how screening mammography affects that risk (Silverman et al., 2001). Women often viewed breast cancer as a progressive disease rarely curable unless caught early. About one fourth of the women believed breast cancer to be their greatest health threat, however, whether these women were those with a family history of breast cancer was not reported. Women often perceived smoking, diet, toxic exposures, and "bad attitudes" as breast cancer risk factors with importance similar to age, sex, family history, and genetics. Women almost universally believed that mammography could detect breast cancer early and that cancers were seldom missed. Women also said the relief from having a normal mammogram outweighed the discomfort and most believed mammography had no downsides, About half of the women believed strongly that mammography was important, and the majority reported that if they were to receive an abnormal mammogram they would be fearful of the outcome. How these findings impacted women's mammography decisions was not reported.

Decision Making Concerning Genetic Testing and Breast Cancer Surveillance

Focus groups were conducted with 66 women ages 24 to 77 either diagnosed with breast cancer or who had relatives diagnosed with breast cancer to better understand decision making regarding breast cancer genetic testing (Tessaro, Borstelmann, Regan, Rimer, & Winer, 1997). All women thought the information from cancer predisposition testing could help reduce uncertainty and assist with making future decisions about medical treatment and cancer screening. In addition, genetic knowledge might motivate them to engage in more lifestyle and dietary measures associated with reduced breast cancer risk.

In another study looking at hypothetical responses to genetic testing for breast cancer in women with a family history of breast cancer, most women stated they would have mammography screening more frequently if they had genetic testing for breast cancer predisposition and the results were positive (Durfy, Bowen, McTiernan, Sporleder, &

Burke, 1999). In another study, women with a positive genetic test for breast cancer predisposition underwent screening mammography more frequently than women with a negative genetic test result (68% compared to 44%) (Lerman et al., 2000). Age related differences were not addressed.

Decision Making Models

Classical decision making model

Classical decision making theories have assumed rational, analytic processing as the 'gold standard' for decision making. The concept of informed decision making in classical decision making models assumes the decision maker assimilates relevant facts and makes a decision based on a set of fixed alternatives. A woman's decision is considered to be more informed if her mental model of mammography more closely resembles that of an informed expert (Broadstock & Michie, 2000).

Health Belief Model and Transtheoretical Model

According to the Health Belief Model, a person's behavior is determined by perception of risk for a certain condition and perceived benefits and barriers to taking action to decrease this risk, which have all been linked to mammography use (Champion & Miller, 1996; V. L. Champion, 1994, 1999; Saywell et al., 1999). How these factors influence the decision making process, however, is not well understood.

The Transtheoretical Model of behavioral change has been used in the context of mammography decision making (personal communication Dr. Victoria Champion April 30, 2003). This model postulates four stages of the adoption of a health behavior -- precontemplation (not doing and not thinking about doing the behavior), contemplation (not doing but considering doing the behavior), action (starting to do the behavior), and maintenance (continuing to do the behavior) (Brenes & Skinner, 1999; Crane et al., 1998; Lipkus, Rimer, & Strigo, 1996; Pearlman et al., 1997; Rakowski et al., 1997).

Naturalistic decision making

A naturalistic perspective is interpretive, looks at the human behavioral processes of how decisions are made in real life, and environment and social context are seen as important (Broadstock & Michie, 2000). This perspective includes subjective, automatic, intuitive decision making processing. The focus is on human behavioral decision making processes and it is thought to be modeled closer to how decisions are made in real life. Naturalistic decision making fits well with grounded theory methodology and addresses some of the concerns associated with assumptions in the classical decision making model.

Summary of the Decision Making Literature

Research related to breast cancer screening has focused on factors associated with women's behavior, rather than on the decision making that preceded the behavior (Lewis et al., 1999). Breast cancer decision making literature is largely focused on choosing treatment alternatives. Mammography decision making literature is focused on compliance and predictors, with little being known about the decision making process women undergo.

Older women making decisions about breast cancer treatment want less involvement in decision making than younger women, however, studies looking at how age impacts decision making in older women without breast cancer were not found. Most decision making research is based on rational decision theories derived from the Utility Model. These theories assume rationality as the gold standard and often view decision making as the process of the decision maker surveying a fixed set of alternatives, weighing the pros and cons, and making a choice. Naturalistic decision making looks at human behavioral decision making processes and is modeled closer to how decisions are made in real life by including automatic, intuitive processing. Naturalistic decision making is interpretive in nature and environment and social context are important (Broadstock & Michie, 2000; Pierce & Hicks, 2001).

Summary of the Literature

Older women with a family history of breast cancer are at greater risk for being diagnosed with and dying of the disease due to both age and family history. In spite of efforts aimed at increasing mammography utilization, including the implementation of Medicare coverage for mammography screening that began ten years ago, mammography utilization in older women remains low. Although older women are at greater risk for being diagnosed with breast cancer, increased age is associated with decreased use of mammography. More research is needed to better understand why older women undergo mammography screening less frequently than younger women. Since women with a family history of breast cancer are more likely to receive screening mammography, it is unclear why as many as half of these women are not receiving regular mammograms and as many as 20% have never had a mammogram (Roetzheim et al., 1996). In addition, why older women with a family history of breast cancer still use mammography less often than younger women with a family history of breast cancer is not understood.

There are a number of factors associated with mammography use. Higher mammography use is associated with having a family history of breast cancer, health care provider mammography recommendation, younger age, higher income, higher education, having health insurance and having a personal history of breast pathology. Lower mammography use is associated with increased age, worsening health status, lower income, and lacking health insurance. In addition, physicians recommended mammography less often to women as their age increased (Lane et al., 2000).

Health care provider factors such as insufficient reminder systems and disagreement with mammography guidelines are associated with decreased mammography utilization (Duijm et al., 1997). Physicians are less likely to recommend mammography to women older than age 75, those with mild dementia, or women in a nursing home (Marwill et al., 1996).

Most research in this area has been correlational and focused on factors associated with increased or decreased mammography utilization rather than the decision making processes women undergo in deciding to have a mammogram. In addition, although several studies have identified that women with a family history of breast cancer are more likely to obtain mammography, studies have reported differential effects of factors that promote mammography use when women with and without a family history of breast cancer are compared.

In spite of numerous studies looking at mammography utilization, the process women go through to make decisions concerning whether or not to pursue mammography screening and the reasons for continued under utilization are not well understood. Although there have been studies addressing factors correlated with mammography utilization in older women with a family history of breast cancer, these studies do not address why increased age is associated with decreased screening or examine factors impacting the mammography decision making processes in these women.

Much of the breast cancer decision making literature has focused on breast cancer treatment decisions. Breast cancer treatment decision making often involves time critical choices whereas mammography screening decision making is made within a different context because there is no known disease present. Research concerning the decision making processes women undergo in making breast cancer screening decisions is limited.

Research concerning the mammography decision making processes women undergo is important because it may lead to a better understanding of why many women underutilize screening mammography. This research is especially important in high risk women such as older women and those with a family history of breast cancer.

Study Purpose and Rationale

This purpose of this study is to describe decision making processes in older women with a family history of breast cancer and to generate a beginning grounded theory concerning how they make screening mammography decisions. It is hoped that the information gained from this study will lead to a better understanding of factors, context, conditions and meanings associated with mammography decision making in older women with a family history of breast cancer.

Grounded Theory

A qualitative methodology was chosen since research addressing how older women with a family history of breast cancer make decisions regarding whether or not to pursue screening mammography has not been described. Grounded theory methodology was chosen to provide an explanatory theory describing the factors, context, conditions and meanings associated with mammography decision making in older women with a family history of breast cancer.

CHAPTER THREE

Research Design and Methods

Grounded theory method was used in this research to generate a beginning grounded theory concerning how older women with a family history of breast cancer make screening mammography decisions. Conditions, context, and meanings that influence the screening mammography decision making processes in these women were identified. The first part of this chapter will discuss the following: symbolic interactionism as the theoretical framework for grounded theory methodology, the philosophical underpinnings of grounded theory, development of grounded theory, grounded theory methodology, and grounded theory analytic processes. The second part of this chapter addresses study research design including sample, setting, recruitment, human subjects' protection, data collection, data analysis, and trustworthiness of the findings.

Symbolic Interactionism as a Theoretical Framework for Grounded Theory

Grounded theory has its roots in symbolic interactionism, which came out of the University of Chicago's school of sociology between 1920 and 1950 (Glaser & Strauss, 1967; Robrecht, 1995; Strauss & Corbin, 1998). George Herbert Mead, a social psychologist, believed that the individual mind and self arises out of a social process; that the communication process is a social act; and that language is communication through significant symbols such as vocal or non vocal gestures (Mead, 1962). Mead's views were later articulated by Blumer, who coined the term 'symbolic interactionism'. This view is based on three premises; that human beings act toward things based on the meanings that the things have for them, the meanings of these things are derived from social interaction, and these meanings are then modified by the person through interpretation and used and revised by the individual to guide and form action (Blumer, 1969).

Symbolic interactionism claims that meaning can only be established through interaction with others. How one perceives and defines reality is largely determined by with whom, with what, and how one interacts (Kendall, 1999). Symbolic interactionism is concerned with the meanings of events to people and the symbols they use to convey those meanings (Baker, Wuest, & Stern, 1992). Non-symbolic interaction is when one responds directly to the action of another without interpreting that action; symbolic interaction involves interpretation of the action (Blumer, 1969).

These basic assumptions of symbolic interactionism, as conceptualized by Mead and elaborated by Blumer, developed into what is known as the Chicago school of interactionism. The Chicago school emphasized the interpretive process in the construction of the meaning of social experience as it is lived (Benzies & Allen, 2001). Blumer suggested that exploratory inquiry is not limited to any particular set of techniques but instead focuses on understanding the participant's world. He also used Mead's discussion of the 'I' and 'me' to help understand the nature of human behavior (Benzies & Allen, 2001).

Symbolic interactionism was proposed by Blumer as an alternative approach to research inquiry since he believed the research approaches used at the time were not designed to develop a close familiarity with the area under study (Blumer, 1969). According to Blumer, exploratory inquiry should not be limited to any particular set of techniques. The goal of inquiry is to help get a clearer picture of what is going on in the area of social life and may involve interviewing of people, listening to their conversations, life-history accounts, letters, diaries, and consulting public records (Blumer, 1969). He also believed the procedure should be adapted to the circumstances and that one should seek participants who are well-informed and acute observers. Early research based on these assumptions involved the researcher observing, recording and analyzing data obtained in a natural setting (as opposed to a laboratory or research setting). Although this process led to a theoretical explanation of events, the analytic processes leading to this theoretical explanation were not described.

The Development and Philosophical Underpinnings of Grounded Theory

In the early 1960s Anselm Strauss and Barney Glaser set out to explain a method of developing theory from systematically collected qualitative data and called it grounded theory (Glaser & Strauss, 1967). Grounded theory is a qualitative research methodology developed for the purpose of generating theory and is derived from the assumptions and theoretical underpinnings of symbolic interactionism (Glaser & Strauss, 1967). The goal of grounded theory is to systematically derive empirically based theories of human behavior and the social world through an ongoing process of constant comparative analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1998). In grounded theory, interpretations of a situation are influenced by a person's social interactions with others and the sociocultural environment in which they exist (Benoliel, 1996).

Glaser and Strauss were both sociologists, although they came from somewhat different backgrounds (K. Smith & Biley, 1997). Strauss came out of the University of Chicago, with its long history of qualitative research, with a doctoral degree in sociology. The University of Chicago, often referred to as the Chicago school of interactionism, was influenced both by symbolic interactionism, conceptualized by Mead (1962) and further developed by Blumer (1969), and by pragmatist writings (Benzies & Allen, 2001; Kushner & Morrow, 2003). Strauss brought to the development of grounded theory the influences of symbolic interactionism and pragmatism as well as the University of Chicago's long history of pioneering and innovating qualitative research approaches (K. Smith & Biley, 1997; Strauss & Corbin, 1998). Some of these influences included the need to go into the field to discover what is going on, the realization that persons act on the basis of meaning, and that this meaning is defined through interaction (Strauss & Corbin, 1998).

Glaser received his doctorate in sociology from Columbia University and was influenced by Paul Lazarsfeld, an innovator of quantitative methods who also used qualitative methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Glaser's training was in the more positivistic Columbia tradition, which emphasized empirical research in conjunction with the development of theory, and he later pursued qualitative research (Kushner & Morrow, 2003; Strauss & Corbin, 1998). One of Glaser's contributions to grounded theory was the need he saw for making constant comparisons between data to identify, develop, and relate concepts (Strauss & Corbin, 1998).

In summary, Strauss brought to grounded theory the Chicago school field research based on symbolic interactionism along with the pragmatist philosophical study of process, action, and meaning to inquiry (Charmaz, 2000). Glaser brought to grounded theory his more positivistic methodological training in quantitative research from the Columbia University (Charmaz, 2000). Glaser and Strauss's work (1967) was revolutionary because it challenged:

> (a) arbitrary divisions between theory and research; (b) views of qualitative research as primarily a precursor to more 'rigorous' quantitative methods; (c)

> claims that the quest for rigor made qualitative research methods illegitimate; (d) beliefs that qualitative methods are impressionistic; (e) separation of data collection and analysis; (f) assumptions that qualitative research could produce only descriptive case studies rather than theory development. (Charmaz, 2000, p. 511).

Glaser and Strauss (1967) describe grounded theory as the discovery of theory from data systematically obtained through research. They contrast grounded theory generated from data with theory generated by logical deduction from *a priori* assumptions. Grounded theory is generated to enable the prediction and explanation of behavior, provide a perspective on behavior, and to give the practitioner understanding and some control of situations (Glaser & Strauss, 1967). Since grounded theory is intimately linked to the data it is based on, it cannot be completely refuted by more data or replaced by another theory (Glaser & Strauss, 1967). Although grounded theory came out of Sociology and Social Science, it is useful in any field as an inductive theory from systematically collected data (Glaser, 1978).

The Separation of Glaser and Strauss

After the publication of *The Discovery of Grounded Theory* (1967), Glaser and Strauss each moved grounded theory methodology in slightly different directions. Glaser published *Theoretical Sensitivity* (1978), in which he discussed what theory is and how to generate and construct theory using processes such as theoretical sampling, theoretical coding, theoretical memos, and identifying a core category (Glaser, 1978). A large part of Glaser's book is devoted to the concept of theoretical sensitivity, which is defined as entering the research setting with as few predetermined ideas as possible in order to remain sensitive to the data and remain open to what is actually happening (Glaser, 1978). Strauss later joined with Corbin in the publication of *Basics of Qualitative Research* (1990, 1998) with the stated intent of providing a set of useful tools for analyzing qualitative data (Strauss & Corbin, 1998). Glaser's response to Strauss and Corbin's book (1990) was to publish *Basics of Grounded Theory Analysis* (1992) in which he is highly critical of their book, especially their use of axial coding and the conditional matrix.

According to Kendall (1999) some of the ideas in Strauss and Corbin (1990) were criticized because they seemed to contradict the original assumptions of grounded theory, especially around the issue of axial coding and use of the predetermined "paradigm model". Axial coding is the process of making connections between categories by putting data back together in new ways after open coding and relating categories to their subcategories around the axis of a category using the paradigm model (Strauss & Corbin, 1998) and is the center of debate between the two grounded theory approaches (Kendall, 1999; Strauss & Corbin, 1990, 1998). Glaser believes that axial coding and using the paradigm model is unnecessary for grounded theory and will produce a combination of imposed and generated conceptual connections between categories rather than allowing these connections to emerge from the data if they are relevant .

Glaser advocates that the codes used and the labels put on codes need to emerge from the data (Glaser, 1978). According to Glaser the grounded theorist starts with open coding where the data are coded line by line. The next step is selective coding for a core variable where coding is limited to the categories that relate to the core variable (Glaser, 1978). Glaser refers to these first two types of coding as substantive coding, which is followed by theoretical coding to conceptualize how the substantive codes relate to one another as the theory begins to develop (Glaser, 1978). Strauss and Corbin advocate the following: open coding, the analytic process through which concepts are identified and their properties and dimensions are discovered in the data; axial coding, the process of relating categories to their subcategories around the axis of a category; and selective coding, the process of integrating and refining the theory (Strauss & Corbin, 1998).

Another difference between the two approaches to grounded theory is the use of the conditional/consequential matrix, a diagrammatic set of concentric circles, introduced by Corbin & Strauss (1990) to help the analyst identify conditions under which events occur that influence the phenomena at many different levels. The center of the matrix is the action pertaining to the phenomena and then precedes outward, i.e. individual, group, organizational, community, national, international levels. Regardless of which level within which the phenomena of study is located, that phenomena will stand in conditional relationship to levels above and below it (Strauss & Corbin, 1990). Glaser, however, believes that the conditional matrix forces theory upon the data rather than allowing the theory to emerge from the data (Glaser, 1972). Glaser believes using the conditional matrix results in a forced conceptual description that may not be relevant to the data. If conditions and context are relevant to the theory, they will emerge in the data and the researcher must trust that the emergence will occur (Glaser, 1972).

Constructivist Grounded Theory

Constructivists believe that what we take to be objective reality is relative to the perspective of the person experiencing it (Charmaz, 2000). Each perspective represents reality to the person having the experience and therefore multiple perspectives or realities are possible. This belief that multiple realities are possible is often referred to as a ‘relative ontology'. There is not one reality that is more correct or more real than another because each reality is created by the social context of the person experiencing it. For example, participants who undergo mammography may have different contextual perspectives about the experience. Although the perspectives may be different from one another, each is experienced as reality by the person having the experience. Based on their specific contextual lens the grounded theorist reveals the context. The constructionist would try to capture these different perspectives through interviews and observations without making judgments about which perspective, or reality, is more correct or better represents the true reality of the mammography experience.

A constructivist grounded theory approach acknowledges the interactive nature of both data collection and analysis. This approach also recognizes that knowledge is not passive. It is more than imprinting data on the mind but involves what the mind does with those impressions (Charmaz, 2000). In qualitative research, what is learned from interviewing the participants is then analyzed by the researcher and during that process is influenced by the researcher's values and beliefs. Constructivism involves a subjective epistemology based on the assumption that observer cannot be totally objective and separate from the observed. Knowledge is therefore a product of the interaction between the researcher and the participants and is mutually created because both contribute to the end product (Charmaz, 2000; Polit & Hungler, 1999).

The present study was based on grounded theory methodology with a constructivist approach as defined by Charmaz (2000) recognizing a relative ontology with multiple realities and the mutual creation of knowledge by the researcher and the research participants. The theoretical framework is based on symbolic interactionism and the grounded theory methodology is based primarily on Strauss and Corbin (1990, 1998).

The Method of Grounded Theory

Grounded theory methodology consists of systematic inductive guidelines for collecting and analyzing data to build middle-range theory to explain the data collected in the study (Charmaz, 2000). The grounded theory process includes conceptualizing the data through coding, defining categories, developing categories in terms of their properties and dimensions and then later relating categories through statements of their relationships. Definitions for terms commonly used in grounded theory can be found in Table One. A grounded theory is one that is induced from the data being studied (Glaser & Strauss, 1967). It is called grounded theory because the theory is grounded in data that is systematically gathered and analyzed (Strauss & Corbin, 1998). Grounded theory seeks to understand the basic social processes of the phenomena being studied offering an orderly rigorous guide to theory development from data that accounts for a pattern of behavior (Glaser, 1978). The aim is to discover the social processes related to human interaction that explain and give meaning to the phenomena under study.

The emphasis of grounded theory inquiry is discovery of the social process that is the subject of the research question by identifying the conditions and contextual factors under which this social process occurs, and developing a theory that describes and explains the social process. The major distinguishing factor between grounded theory and other qualitative research methods is its emphasis on theory development (Eaves, 2001; Strauss & Corbin, 1998).

Table 1

Definition of Grounded Theory Terms

axial coding: the process of relating categories to their subcategories. The researcher starts putting the pieces of the puzzle together to explain what is going on in the data. It is termed 'axial' because coding occurs around the axis of a category, which serves as the focal point, and relationships of the subcategories to the category are identified (Strauss & Corbin, 1998).

categories: groups of similar concepts derived from the data which represent central ideas from the data. A category consists of several concepts with one or more common elements. Categories should be distinct from one another. For example, fruits and vegetables are categories. They have common elements among themselves and are distinct from one another (Strauss & Corbin, 1998).

context: the circumstances or setting in which an event occurs that give meaning to the phenomena. For example an American flag can have different meanings such as liberty or oppression depending on the context (Patton, 2002).

conditional matrix: an analytic diagram that maps the range of conditions related to the research phenomenon. Strauss and Corbin (1998) represent this matrix as a set of circles to help the researcher identify conditions under which events occur that influence the phenomena from smaller to larger levels of influence (i.e. individual, group, family, organizational, community, regional, national, global).

constant comparative analysis: the process of taking two or more bits of data and comparing them to see if they are conceptually the same or different (Strauss & Corbin, 1998).

core category: the core or central category describes the main point of what is going on in the data, pulls all the other categories together into an explanatory whole, and accounts for variation within categories. A core category may evolve out of existing categories because it best describes the central idea of the phenomena or a more abstract conceptual term may be needed that ties together the other categories under the core category (Strauss & Corbin, 1998).

emergent design: the process of adjusting one's inquiry plans and strategies in response to what is learned as the study unfolds. It is the openness to adapt inquiry methods as the study progresses in response to what is found in the study (Patton, 2002).

naturalistic inquiry: research that takes place in a real world setting where the researcher does not attempt to manipulate the phenomena being studied (Lincoln & Guba, 1985).

paradigm model: an organizational system designed to assist with identifying patterns in the data relating of categories to the core category call the paradigm model. This model consists of context, conditions (sets of events or happenings that influence phenomena), actions/processes, and consequences (Strauss & Corbin, 1990, 1998).

theoretical memos: Theoretical memos are a record of the researcher's thinking as data is coded and categories are developed, organized and refined (Strauss & Corbin, 1998).

theoretical sampling: the process of data collection for generating theory where the researcher decides what data to collect next in order to further develop the emerging theory. Sampling for the type of data needed to help develop the theory is called theoretical sampling (Strauss & Corbin, 1998).

theoretical saturation: the point at which the investigator decides additional analysis will contribute no new information to the theory because information being collected from research participants has become redundant and no new codes are being generated (Strauss & Corbin, 1998).

theoretical sensitivity: Theoretical sensitivity involves entering the research setting with as few predetermined ideas as possible in order to remain sensitive to the data and remain open to what is actually happening (Glaser, 1978).

Grounded theory is considered a qualitative methodology using systematic inductive guidelines for collecting and analyzing data to build middle-range theoretical frameworks to explain the data collected (Charmaz, 2000). It begins with identifying a research question and involves simultaneous data collection and analysis (K. Smith & Biley, 1997). Grounded theory methods specify analytic strategies, not data collection methods (Charmaz, 2000). The hallmarks of grounded theory methods include constant comparative analysis, emergent design, theoretical sampling, theoretical saturation, and theoretical sensitivity.

Grounded Theory Data Analysis Techniques Based on Strauss and Corbin

Grounded theory data analysis involves the process of looking at the data to answer the research question or questions concerning the phenomena being studied. The process involves several types of coding (open, selective, and axial), constant comparative analysis, writing and analyzing memos, and theoretical sensitivity. First the data are coded, analyzed and concepts identified; next the concepts are organized into categories or themes, which come from reducing the data while retaining the essential story. Patterns are then identified describing how groups of properties align themselves along a continuum. For example, if the study involved how women come to discover breast lumps, an example of a pattern that might be discovered in the data is *discovery, suspicion, seeking information, and confirmation.* Discovery, suspicion, seeking information, and confirmation all represent categories in the data and each category has properties and dimensions of variation. The dimensions of suspicion, for example, can range from being immediate, delayed or having no suspicion.

Paradigm Model

Strauss and Corbin (1990, 1998) advocate an organizational system designed to assist with relating of the categories to the core category they call the paradigm model, which consists of context, conditions (sets of events or happenings that influence phenomena), actions/processes, and consequences. The central or core category best represents what is going on in the data, pulls all the other categories together into an explanatory whole, and accounts for variation within categories. A core category may evolve out of existing categories because it best describes the overall research phenomena or a more abstract conceptual term may be needed that ties together the other categories under the core category (Strauss & Corbin, 1998).

The paradigm model is designed to help the researcher look at the research phenomenon in terms of context, conditions, actions/processes, and consequences and their relationships to each other. Phenomena are what go on in the data such as repeated patterns of happenings, events or actions concerning what people do or say in response to certain situations. In coding, phenomena are labeled as categories and the central phenomenon becomes the core category. The paradigm model therefore helps the researcher identify patterns and relationships between the core category and the categories and also relationships among the categories.

Diagrams

Diagrams are a way to show the density and complexity of the theory. The goal of a diagram is a clear representation of the theory that synthesizes the major categories and concepts and their relationships to one another (Strauss & Corbin, 1998).

Integrative diagrams

An integrative diagram synthesizes the major concepts and categories in the theory and represents how their connections and relationships. This diagram can represent the entire theory or some aspect of the theory. For example a diagram may specifically address one category and all its subcategories. Through data coding, reading and sorting memos, and constant comparison the researcher is able to able to write a descriptive story and translate this story into an integrative diagram (Strauss and Corbin, 1998).

Coding

Open coding

Open coding is the analytic process through which concepts are identified and their properties and dimensions are discovered in the data (Strauss & Corbin, 1998). This process involves coding the data line by line to identify concepts and discover their properties and dimensions. Properties are characteristics of the category that define and give meaning, and dimensions refer to the range along which the properties of the categories vary. Similar concepts are then grouped into categories based on their ability to explain what is going on in the data. Open coding is a process used to open up the data and discover the thoughts, ideas, concepts and meanings in the data. Concepts that reach the status of a category are abstractions since they represent not just one individual's story, but the stories of many individuals (Strauss & Corbin, 1998). A category consists of a group of similar concepts derived from the data that stand for some central idea from the data.

Axial coding

Open coding is followed by axial coding where the categories are systematically developed and linked with subcategories. Axial coding is the process of relating categories to their subcategories. In essence, the researcher starts putting the pieces of the puzzle together to explain what is going on in the data and begin building the theory. It is termed 'axial' because coding occurs around the axis of a category (Strauss & Corbin, 1998). The category serves as the focal point and relationships of the subcategories are in relation to or rotate around the category. Axial coding is a way of making connections between the categories to start making sense of the data. Axial coding focuses on the conditions that give rise to a category, the context in which it occurs, the actions or interactions associated with the category and the consequences of those actions (Kendall, 1999; Strauss & Corbin, 1998). In a study looking at processes related to breast cancer diagnosis, if 'suspicion' is a category, what are the conditions under which suspicion occurs? What is the context? What actions are associated with suspicion? Does the woman ignore the suspicion, go to the doctor, ask a friend, etc. What are the consequences, biopsy, cancer, delayed diagnosis? These questions can help the researcher identify the relationships of categories to subcategories in axial coding.

Selective coding

Selective coding is the process of integrating categories into a larger theoretical scheme and refining the theory (Strauss & Corbin, 1998). Theoretical memos are used to help fill in and develop categories. Diagrams can be used as a visual tool to represent relationships among concepts and categories (Strauss & Corbin, 1998). At this point the categories no longer represent individual stories but the integration of many stories of individuals or groups. Categories need to be broad enough and flexible enough to represent all the participants in the research study. The researcher is trying to explain what is going on in the data. For example, under these conditions this set of events occurs within this particular context. This then leads to a particular set of actions/interactions and results in these consequences. Major categories are refined and integrated around the core category to form a larger theoretical scheme and begin to take the form of theory. This is the final step in the analysis, making it all come together, which results in a theory (Strauss & Corbin, 1998).

During selective coding, the first step is choosing a central or core category that best explains what the research is all about. The core category has analytical power in that it has the ability to pull the other categories together to form an explanatory whole. It may evolve out of an existing category or it may be a more abstract term that captures what is going on in the research. The other categories are then related to that central idea to form the theory (Strauss & Corbin, 1998).

Constant Comparative Analysis

Comparative analysis involves taking two bits of data and comparing them to see if they are conceptually the same or different (Corbin, 2003). It is a central feature of grounded theory and is referred to as the constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Constant comparison allows a researcher to identify patterns and relationships between patterns (Glaser, 1978). In grounded theory the initial or emerging theory is constantly being tested against the data from which it was generated (Mertens, 1998). The making of comparisons is a necessary step in identifying and categorizing concepts. Comparisons help the researcher discover specific dimensions of the concept or category. If two pieces of data are conceptually the same, the researcher puts the same label on them, but if they are conceptually different, then each has a different label. The researcher is comparing the two pieces of data conceptually when determining if they will have the same or a different label (Corbin, 2003).

The process of putting similar concepts into categories involves the researcher making some comparisons by looking at the concepts and trying to discern what the common element might be. What do they share in common? Are all of these concepts at the same level? Does one seem more to explain more than the others? (Corbin, 2003).

Memos and Field Notes

Memos are specialized types of written records that may contain a description of what has been observed, products of analysis and how the researcher conceptualizes the data means as the study progresses. The three types of memos commonly used in grounded theory are field notes, methodological memos, and theoretical memos. Memo writing is a constant process used by the researcher to keep track of observations, thoughts and ideas throughout the process of data collection and analysis. Regardless of the type of memo, it is important to write a memo as soon as possible after the event or idea occurs. Memo writing can help the researcher look at the data in new ways and keep track of the researcher's own attitudes, feelings, and experiences as the data is collected and analyzed (Corbin, 2003).

Field notes or observational memos

Field notes are a record of what the researcher hears and observes in the field and should contain everything the researcher thinks is worth noting. They contain descriptive information such as where the observation took place, who was present, what the environment was like, and what social interactions or activities took place (Patton, 2002). Field notes may also include the tone of voice of someone present, or a description of facial expressions or body language. Field notes, however, are limited to what one observes.

Methodological memos

Methodological memos are observational notes related to the methodological process and any resulting decisions related to changes in methodology (Polit & Hungler, 1999). They consist of written comments by the researcher related to the study methodology such as something that happened impacting the way the study was conducted or quality of the data. Examples include notes about wording of the interview questions, why the interview was lengthened or shortened, how observations were made, what the researcher did that helped or hindered the methodological process and subsequent changes to how observations will be made or interviews conducted in the future as a result. For example in the this study one of the participants did not understand the word "mammography" in the interview questions so wording in the questions for subsequent interviews was changed to use the word "mammograms".

Theoretical memos

Theoretical memos are a write-up of ideas about codes, concepts, and their relationships as they strike the researcher while coding (Glaser, 1978). They are a record of the researcher's analytic thinking and decision making as data is coded and categories are developed, organized and refined (Strauss & Corbin, 1998). Memo writing is a constant process used by the analyst to keep track of thoughts and ideas throughout the process of data collection and analysis. Theoretical memos are the basis of ones conceptualization of the data as analysis proceeds.

Theoretical memos are different from field notes. Field notes are actual events or observations that occur in the field. They are not interpretive (Corbin, 2003). Field notes need to be kept separate from theoretical memos. In contrast, theoretical memos are a way for the researcher to explore ideas (Corbin, 2003). For example, writing a code can bring an idea which leads to a memo. The researcher should always interrupt coding to write memos so ideas are not lost (Corbin, 2003). Memos also help the researcher keep track of attitudes, feelings, and experiences as data is collected and analyzed and help the researcher follow a line of thinking and see patterns emerge in the data (Corbin, 2003).

Theoretical Sensitivity

In grounded theory, the theory needs to explain what is going on in the data, the concepts and categories must fit, and the theory needs to be relevant. The researcher needs to be theoretically sensitive in order to have theoretical insight into the data along with the ability to use these insights in the development of theory as the theory emerges from the data. Theoretical sensitivity involves entering the research setting with as few predetermined theoretical ideas as possible while at the same time having some experience with the phenomena in order to remain sensitive to the data and remain open to what is actually happening (Glaser, 1978). A grounded theory can have both concepts and theoretical elements that emerge from the data in addition to those that already exist in other theories or in the literature that are found to fit with the data and have relevance. If the researcher has a preconceived theory and tries to fit the data into that theory then theoretical sensitivity will be lost. The researcher needs to remain sensitive to the data and let the theory emerge rather than try to fit the data into pre-existing hypotheses and theoretical biases (Glaser, 1978; Glaser & Strauss, 1967).

Asking questions of the data is one technique that can help the researcher develop theoretical sensitivity. Good questions are ones that lead the researcher to answers that help develop the theory. For example, there are sensitizing questions that help the researcher understand what the data might be indicating such as: "What is going on here?" "Who are the actors involved?" and "What are the various actors doing?" There are also theoretical questions that help the researcher see process and variation and to make connections among concepts. Examples of these questions include: "What would happen if…?" "How do events and actions change over time?" "How do these events affect what I am seeing or hearing?" and "What is the relationship of one concept to another?" (Strauss & Corbin, 1998). The researcher needs to systematically relate categories into theory. The researcher can also ask questions of the emerging theory such as "What does the theory do?" or "How is it conceived?" (Glaser, 1978; Glaser & Strauss, 1967). These kinds of questions help the researcher move from description to abstraction in developing the theory.

Another technique to help develop theoretical sensitivity is to use what Strauss & Corbin (1998) refer to as theoretical comparisons, which is a form of comparative analysis. This process involves using properties from comparative incidents to help give meaning to something that is happening in the data and to enlarge the researcher's thinking. For example, if a research participant said that the pain of having a mammogram reminded her of being in hard labor, the researcher could think about the properties of the experience of being in labor and compare those properties in an abstract way to the experience of having a mammogram to gain theoretical insight into the research participant's experience.

Theoretical sensitivity involves having theoretical insight into your data and the capacity to generate concepts and see theoretical relationships (Wuest, 2003). The researcher needs to be open to the concepts and categories that emerge from the data and to think theoretically in terms conceptualizing and formulating a theory as it emerges from the data (Glaser & Strauss, 1967).

Emergent Design

Emergent design is the process of adjusting one's inquiry plans and strategies in response to what is learned as the study unfolds (Schwandt, 2001). The researcher needs to allow for emergent issues as the study progresses that call for flexibility and adaptations in sampling procedures, interview questions, and ways of generating data that may help the researcher better answer the research question. Although the researcher gives careful thought to the research design when planning the study, research design using grounded theory method involves starting with a general approach to a study rather than a detailed plan. This plan needs to be flexible enough to allow for modifying the design to accommodate issues that emerge as the study progresses. In this respect the research design evolves or emerges as the research progresses based on increased understanding of and sensitivity to the phenomena being studied. Data analysis guides further data collection and specific sampling decisions evolve during the research process (Strauss & Corbin, 1998). It is a way of planning for broad contingencies.

Theoretical Sampling

Theoretical sampling involves selecting incidents for data collection that are guided by the emerging theory; as you ask questions of your data, you will begin collecting data that will help you fill in gaps in your theoretical formulation (Mertens, 1998). It is used to develop and refine emerging categories and help fill in the gaps. Sampling is focused on a specific issue looking for precise information that will help shed light on the emerging theory (Charmaz, 2000). "Theoretical sampling helps to define the properties of our categories; identify the contexts in which they are relevant; specify the conditions under which they arise, are maintained, and vary, and to discover their consequences" (Charmaz, 2000, p. 519). Theoretical sampling involves sampling based on our concepts that represent variation or fill in a gap in the developing theory (Corbin, 2003). Specific data sources are chosen for what they can contribute to the development of the emerging theory (Wuest, 2003).

In grounded theory the researcher is concerned with uncovering the situated, contextual and core social processes. Sampling is purposeful in that these social processes need to be shared and experienced by the individuals who make up the research sample (Cutcliffe, 2000). At the beginning of a grounded theory study there are no predetermined limits on the number of participants. The selection of participants or other data sources is a function of the emerging theory. Participants are selected and interviewed until they are saying nothing new about the concepts being explored (Cutcliffe, 2000). Sample size is determined to be sufficient when the key concepts that have been identified from the data collected have reached theoretical saturation point, which means that no new open codes in subsequent collected data emerge (K. Smith & Biley, 1997).

Theoretical Saturation

In grounded theory, the exact sample size cannot be known in advance because data collection ends when theoretical saturation has been achieved. Theoretical saturation occurs when no new properties, dimensions, or relationships emerge during data analysis (Strauss & Corbin, 1998). It is about reaching informational redundancy and hearing the same perspectives repeatedly (Corbin, 2003) and reaching the point at which additional analysis contributes no new information to the theory (Glaser & Strauss, 1967). Criteria for theoretical saturation include: no new information about a category is obtained during coding, and the theory seems to account for variability in the phenomena of interest (Glaser & Strauss, 1967; Strauss & Corbin, 1998). In other words, the theory seems reasonably complete to the researcher doing the analysis.

Research Design and Methodology

The present study assumes a constructivist grounded theory approach as previously described with a relative ontology and subjectivist epistemology (Charmaz, 2000). This approach allowed the researcher to study screening mammography decision making within the social contexts of being older and having a family history of breast cancer. Decision making was viewed from a naturalistic perspective as opposed to a rationalistic perspective. A naturalistic perspective is modeled closer to how decisions are made in real life because it includes subjective, automatic, intuitive decision making. The focus is on human behavioral decision making processes. Naturalistic decision making is interpretive in nature, and environment and social context are important (Broadstock & Michie, 2000). Study data was be used to support the naturalistic decision making model but rather naturalistic decision making was used as a guiding perspective to inform the interpretive process. Naturalistic inquiry was used in that the settings were natural and there was no attempt to manipulate the environment, the participants, or the interactions (Lincoln & Guba, 1985; Patton, 2002). The phenomena were allowed to unfold naturally and there was no predetermined course of action such as there might be in a laboratory. Participants were interviewed in places and under conditions that are natural to them, such as their place of residence.

The purpose is to describe and explain the mammography decision making processes of older women with a family history of breast cancer using grounded theory methodology. Qualitative data about mammography decision making was collected using open-ended semi-structured interview questions to identify factors, conditions, context, and meanings that influence screening mammography decision making in study participants. Semi-structured interview questions started very broadly. As the study progressed and the research problem was better understood, questions became more specific concerning the mammography decision making experience.

Sample

Women age 65 and older with one or more first-degree blood relatives (parent, sibling, child) diagnosed with breast cancer were included in the study. A first-degree blood relative is one who shares 50% of one's DNA and includes parents, siblings, and children (Bennett, 1999). Age 65 and older was chosen because although women age 65 and older comprise only about 14 percent of the population nearly half of breast cancer cases and more than half of breast cancer mortality occurs in this age group (Smith-Bindman et al., 2000).

Participant inclusion criteria

1. be a female age 65 or older
2. have at least one first-degree blood relative with a diagnosis of breast cancer (parent, sibling, child)
3. ability to hear adequately and understand English
4. ability to articulate her experiences and participate in an interview
5. ability to provide informed consent and willing to participate
6. no personal history of breast cancer, ductal carcinoma in situ, breast implants, or mastectomy
7. no cancer diagnosis (except non melanoma skin cancer) the past 10 years

Sampling

Sampling techniques for this study included purposeful, snowball, and theoretical. Sampling was initiated with purposeful sampling, which means that participants were chosen because they met certain criteria related to the phenomena of interest and can offer rich information about the phenomena. Snowball sampling was also used, which involves talking to participants and asking them who else to talk to about the study in order to help recruit potential participants to obtain further depth about the phenomena (Patton, 2002). This was accomplished by speaking with health professionals in the community, community leaders for programs providing services to older persons, working with other researchers at OHSU recruiting similar populations, and the participants themselves.

Theoretical sampling, as previously described, was used to fill in the gaps in the emerging theory. To help achieve a broad variation in the mammography decision making experience, an attempt was made to have participants in the study that both have received their most recent mammogram according to screening recommendations and those who have not. This was done through theoretical sampling by creating separate recruitment materials targeted specifically to women who have not had a mammogram in the past three years. This time frame was chosen because most of the screening guidelines agree that mammograms are recommended at least every two years for women age 65 and older (AGS, 1999; Institute, 2002; R. A. Smith et al., 2005).

It was expected that the ethnic representation of the sample would be similar to the Oregon population. Oregon population in 2002 by race was white persons 92%, Hispanic/Latino 8%, Asian 3%, Black/African American 1.6%, and American Indian/Alaska Native (United States Census Bureau accessed 12/3/03 at 1.3% http://quickfacts.census.gov/qfd/states/41000.html). Since this sample was small, it was also expected that not all race categories may not be represented.

Setting

Participants were interviewed in their place of residence, in a private location in the facility from which the participant has been recruited, or at a location mutually agreeable to the participant and the interviewer. Most participants were interviewed in their place of residence. In several cases the place of residence was a senior living facility from which the participant was recruited. Two participants were interviewed at a relative's place of residence and two participants were interviewed at a facility outside their home at their request. All initial interviews took place in person. Some follow up information was obtained by talking with the participant over the telephone.

Human Subjects Protection

IRB approval was obtained from OHSU February 6, 2004. Permission to conduct the study was also obtained from the OHSU Cancer Institute (OCI), which is required prior to OHSU IRB approval. On May 25, 2004 a Project Revision/Amendment Form was submitted to the Human Subjects Committee for additional recruitment materials specifically targeted to women who had not had a mammogram in the past three years and this was approved.

Written informed consent was obtained from each participant using a HIPAA compliant consent form prior to being enrolled in the study. Subjects were informed that participation was voluntary and that they had the right to withdraw from the study at any time. Confidentiality was protected by removing identifying information from the data collected and using combination number letter codes for participant identification on all records. Data was kept in locked file cabinets or password protected on the computer.

Each participant was informed of the study purpose, potential risks and benefits, who to contact concerning study information, that participation was voluntary and they had the right to withdraw at any time. Participants were informed that they could choose not to respond to specific questions if they wished and they could ask to have the interview terminated at any time. One participant asked to have the interview terminated and rescheduled when her family arrived for a visit and the interview was re-scheduled for the following week.

Since the purpose of the study was to identify factors associated with the mammography decision making processes in older women with a family history of breast cancer, the potential direct benefit to the participants is small. There may be some participant benefit from having the opportunity to talk to the researcher and share their experiences during the interview process or there may be no direct benefit to the participant for study participation. Potential harm from study participation is also small. Although some participants may have found certain questions or topics distressing, no participants chose to withdraw from the study and there were no adverse events associated with the interviews. Several participants became sad or tearful recalling family members who had died, but this was transient.

Recruitment Procedure

Recruitment began after IRB approval was obtained. Community based recruitment methods were used including group presentations, attendance at community health events, distribution of flyers, and newsletter articles. Flyers were distributed to community and senior centers, groups of older adults, residential facilities for older adults, community organizations, community events, such as Race for the Cure, and appropriate health care facilities. Permission was obtained to give short presentations about the study to appropriate groups attending health related talks. Recruitment flyers and newsletter articles included information about the study and contact information for potential participants to call to obtain more information (see appendix).

Residential centers for older adults have the potential to reach the target population, although if they have onsite health care facilities there is the potential for selection bias toward women who have had mammography screening. For this reason recruitment at these facilities was limited. Flyers were distributed at a variety of locations including organizations such as the Eagles, the American Legion, Four-H adult volunteers, and community and senior centers. Flyers were also distributed to locations such as a low income clinic, chiropractic office, hair salons, car repair shops, grocery store bulletin boards in an attempt to reach a broader variety of participants. Newsletter articles, attending community events, and networking with other researchers were the most effective recruitment strategies.

Initial contact was usually through the potential participant contacting the researcher directly by telephone or by directly speaking to the researcher at a community event or health talk. In a couple instances the potential participant gave their contact information to a health professional from another research study in which they were participating and specifically requested to have the researcher call them with information about participation in this study. Potential participants were contacted by the researcher and eligibility was determined. If the woman was eligible she was informed of the research purpose, procedure, potential risks, and potential benefits of study participation and then invited to participate. Participants who were not eligible were thanked for their time and all contact information was destroyed. If a participant meets eligibility criteria and agree to participate in the study, an appointment is set up to review and sign the research consent form and conduct the interview.

Data Collection Procedures

Once a research participant was determined to be eligible for the study and had agreed to participate, an interview appointment was set up. Prior to the scheduled interview appointment the researcher called to confirm the appointment and answer any questions. Upon arrival the researcher greeted the participant and asked where she would like the interview to take place and where she would be most comfortable. The study was again explained and written consent obtained prior to beginning the study interview. This process also allowed the participant to become comfortable with the researcher and engage in conversation prior to beginning the interview. A conversational style was used for the interviews.

All interviews were conducted by the same researcher. Initial participant interviews took one to two hours. Data was collected by using semi-structured interview questions (see appendix for questionnaires). All interviews were tape recorded with the participant's permission. Tapes were transcribed after the interview either by a transcriptionist or by the researcher for data analysis purposes. References to names or locations made during the interview were taken out during the transcription and replaced with notations such as [mother's name] or [name of small city]. Data was stored in a secure locked location to protect patient confidentiality. Participants were identified by a number letter code in computer files containing data, transcriptions of tape recordings, field notes, memos and data input into *NVivo*. During the study a file folder was kept for each participant filed by the number letter code which contained original eligibility forms, consent forms, contact information, and demographic information forms. This information was kept in a locked file cabinet.

Some participants were interviewed either in person or by telephone a second time to clarify information from the initial interview, obtain additional information needed for theoretical sampling, or to provide feedback on concepts and themes that emerge from the data.

Demographic Variables and Descriptive Data

Demographic and descriptive data was collected at the end of the first study interview by questionnaire and included: age, ethnicity, education, family history of breast and other cancers, mammography use, breast self exam practices, most recent clinical breast exam, whether or not the participant has Medicare or other health insurance, and any personal major health problems (see Appendix). All data was obtained by self-report. The demographic questionnaire was administered by the researcher at the end of the initial semi-structured interview.

Semi-Structured Interview Questions

A semi-structured interview based on grounded theory according to Strauss and Corbin (1998) was used to collect interview data. Initial questions were broad and became more focused as the interview progressed. The first set of questions was related to the factors associated with mammography decision making processes. These questions addressed how the woman went about making a decision to have or not have a mammogram, what went into this making this decision, and what factors she considered. Questions were also asked about sources of mammography information, whether the woman thought mammography had any benefits or downsides, her previous experience with mammography, anything she may have heard or read about mammography and whether or not these factors influenced her decision about having a mammogram.

The second set of interview questions was used to identify conditions, context, and meanings influencing screening mammography decision making processes. These questions asked about age (being an older woman), family history of breast cancer, how she perceived her breast cancer risk, and any influence health care provider recommendation may have had on her decision to have or not have a mammogram (see Appendix).

Data Analysis

Data Coding

In grounded theory, coding is the analytic process through which data are conceptualized and integrated. This process involves making comparisons and asking questions of the data. Three types of coding were used in the analysis: open coding, axial coding, and selective coding.

Open coding was used first. Open coding is the analytic process through which concepts were identified and their properties and dimensions were discovered in the data. This process involved coding the data line by line to identify concepts and discover their properties and dimensions. Open coding was followed by axial coding, where the categories were systematically developed and linked with subcategories using the paradigm model as a guide. Selective coding was then used to integrate and refine the theory. A core category was identified and categories, subcategories, and concepts were organized around the core category to form a larger theoretical scheme and begin to take the form of a theory. Theoretical memos were used to help fill in and develop the theory.

Field Notes and Memos

Field notes were kept to record what was observed in the participant interviews. They contain descriptive information such as: where the observation took place, who was present, what the environment was like, and what social interactions or activities took place. For example "This 80 year old woman lives in rural Oregon in a mobile home park. She lives alone and the interview took place in her living room without interruption". Field notes were kept using a computer that is password protected. Field notes were written as soon as possible after the interview took place so important information was not lost.

Methodological memos were kept to record methodological issues that came up during the study. For example, notes about re-wording an interview question to make the question clearer.

Theoretical memos were recorded using Microsoft Word. Ideas were recorded as soon as possible after they occurred. In addition, a spiral notebook was kept with the researcher as much of the time as possible so theoretical memos could be recorded as ideas occurred. For example, "after going back to the data I decided that *worry* and *peace of mind* cannot happen at the same time. *Worry* must be a consequence and not a condition. I will need to modify my diagram". All memos and field notes were dated.

Constant Comparison

Constant comparison was used throughout the data analysis. It is a central feature of grounded theory and involves taking two bits of data and comparing them against each other to see if they are conceptually the same or different. For example, the researcher can compare interview sections from several participants in response to a particular question to see what the common element might be, identify similarities and differences, and whether or not they describe the same concept. If the concepts are different among the interview sections, do some of the concepts explain more than others and are the concepts at the same level? Data is compared with other pieces of data; concepts and categories are also compared and contrasted to gain greater insight and perspective. Constant comparison allows a researcher to identify patterns in the data and relationships between these patterns (Corbin, 2003; Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998).

Data Analysis Using NVivo Software

NVivo qualitative analysis software by QSR was used to assist with management of the qualitative data. *NVivo* is a multi-functional software system for the development, support and management of qualitative data analysis. It is used for a wide variety of tasks from complex theory-constructing and testing to very quick analysis of small or large bodies of text. *NVivo* allows the researcher to import text or portions of text from each interview under a pseudonym or code. Data can be coded, categories can be created and pieces of text can be linked to one or more categories. Categories can then be linked to each other in a tree-like structure to assist with understanding how categories relate to one another. Memos can also be entered into the software to allow the researcher to make notes concerning the data analysis. In this study, the software was used to help organize, code, and manage the data but not for analysis.

Strategies for Enhancing Quality of Data Analysis

Several strategies were used to help ensure the trustworthiness and authenticity of data analysis. Strategies used to address data credibility, conformability, and transferability will each be described separately.

Credibility

Credibility has to do with how much confidence one has in the truth of the data. Strategies to enhance credibility include prolonged engagement, triangulation, member check, and expert panel feedback (Patton, 2002; Polit & Hungler, 1999). In the present study, prolonged engagement was addressed by allowing sufficient time during the interview process to establish a rapport with the participant and collect the necessary data. Two types of triangulation were used. Time triangulation was used by interviewing some participants a second or third time to collect additional data related to the mammography decision making process. By collecting data at more than one time point findings from the first interview can be verified and clarified if necessary. Analyst or investigator triangulation is when more than one researcher analyzes the data independently (Patton, 2002; Polit & Hungler, 1999). In this study, dissertation committee members, doctoral students, post doctoral students, and faculty skilled in qualitative analysis assisted with data analysis.

Member check involves getting feedback from study participants as the analysis progresses regarding the emerging study findings and interpretations (Polit & Hungler, 1999). Member check was achieved by sharing the emerging study interpretations and proposed theoretical model with selected study participants and obtaining their feedback. Participants were given a copy of the study categories with definitions, the latest analytic diagram, and several paragraphs describing study findings and what the diagram means. The researcher explained the diagram and asked for feedback from the participant and if it represented a credible account of their experience. Participant feedback was then integrated into the data analysis and integrative diagram.

Confirmability

Confirmability refers to the objectivity or neutrality of the data such that there would be agreement between two or more independent people about the data's relevance or meaning (Crestwell, 1998; Guba & Lincoln, 1994). An audit trail can be kept to enhance confirmability (Lincoln & Guba, 1985; Polit & Hungler, 1999). That is a systematic collection of materials and documentation that someone else could follow that would allow them to come to conclusions about the data. Records the researcher kept for an audit trail included the following: transcribed data with identifiers removed, field notes, theoretical memos, methodological memos, interview guide and demographic questionnaire, current and previous dissertation drafts, code lists, Powerpoint slides of the emerging model, and notes from meetings with dissertation committee members and from seminars where any aspect of the study was discussed. All of these documents were available for review by the dissertation committee.

Transferability

Transferability refers to the extent to which the findings can be transferred to other groups or settings. Findings in qualitative research are contextually bound and the degree of transferability is related to the degree of similarity between the two contexts. If the two contexts are sufficiently congruent then findings from the originating context may be applicable to the receiving context (Guba & Lincoln, 1985). The researcher needs to provide enough description and detail about the research setting, processes, and context to allow someone else to make a judgment about contextual similarity (Polit & Hungler, 1999). In this study the documents in the audit trail should provide enough description and detail for someone to make a decision about contextual congruence regarding transferability of the study findings to a different context.

CHAPTER FOUR

Results

The purpose of this study was to generate a beginning grounded theory concerning how older women with a family history of breast cancer make screening mammography decisions. Grounded theory methodology was used to analyze data from interviews with women age 65 and older having one or more first-degree relatives diagnosed with breast cancer. Results indicate that women with a family history of breast cancer have a heightened awareness of their breast cancer risk and are "always on guard for breast cancer" because breast cancer is an ever present threat in their lives. The decision to begin having annual mammograms is often the result of participants being "more aware" of their breast cancer risk after having a family member diagnosed with breast cancer. As one woman put it, "I need it more than the average woman."

Women vary in how on guard they are for breast cancer. Some women have a high level of being on guard because of the breast cancer in their family. They say they "worry about it" or even say "I think I'll get it" as if breast cancer were a certainty. These women report extraordinary vigilance with having annual mammograms and efforts to take charge of their health to prevent breast cancer or find it early. For other women breast cancer is only an underlying threat and they have a lower level of being on guard. Women who say they do not worry much about things in general tend also not to worry about breast cancer. They "don't dwell on it", yet remain vigilant with their mammograms and efforts to take charge of their health. Some women have a low level of being on guard because they believe increased age lowers breast cancer risk. These women sometimes decide not to have mammograms because they think they no longer need them.

Participants almost universally reported strong faith in mammography technology and often went to extraordinary efforts to have their annual mammograms. They believe the mammogram will find breast cancer early, and may believe "my life depends on it." As one woman put it "by the time you find a lump it's too late, mammograms are better." Information they received about mammography disadvantages is often ignored, even in women where mammography missed breast cancer in a close relative. Women had elaborate tracking systems for when mammograms were due, often scheduled their own mammogram, and reported worry when awaiting mammogram results, especially when a mammogram recall was involved. A mammography recall is when a woman is called back for more mammography x rays or other follow up testing such as ultrasound, either because the mammogram picture was not clear or because something was found on the mammogram that requires follow up. They talked about the "assurance" and "peace of mind" when they received a negative mammogram result and viewed it as meaning they were "OK for another year." This assurance from a negative mammogram was so strong for some women that breast self-exam (BSE) and clinical breast exam (CBE) were seen as not very important. Participants often practiced BSE irregularly or infrequently, and many reported not receiving regular CBE. Women deciding not to have mammograms also talked about faith in the technology and peace of mind. Under these conditions, the peace of mind comes from both believing they are at lower risk and also from not having any perceived signs or symptoms of breast cancer.

This chapter will describe characteristics of the sample, explain the categories and codes, and present the initial grounded theory of decision making in older women with a family history of breast cancer. A model or diagram of the grounded theory will be presented and described that shows the relationships of the categories to each other and to the core category.

Sample

The sample consisted of 16 women age 65 and older with one or more first-degree blood relatives (parent, sibling, child) diagnosed with breast cancer. Ages of the women ranged from 65 to 85 with a mean age of 73.5. None of the women had a breast cancer diagnosis. One participant reported having colon cancer diagnosis 14 years ago. No other participants reported a personal history of cancer, with the exception of non melanoma skin cancer. Characteristics of the sample can be found in Table 1.

It was expected that the sample in this population would be similar to the Oregon population by race. Since this sample was small not all race categories were represented, which is a limitation of the present study. All participants reported being Caucasian.

Women in the study had a fairly high level of education with all participants reporting they graduated from high school and 10 women reporting one or more years of college. All women reported one or more health problems. The most common health problems reported were hypertension (six women), arthritis (four women), hypercholesterolemia (two women), and diabetes (two women). Half of the women lived alone and half lived with a family member. Most women lived in their own home or apartment, one in assisted living, and two in senior retirement housing complexes.

Family History of Cancer Summary

Ten women reported one first-degree relative with breast cancer. Five women reported two relatives, and one woman reported three first-degree relatives diagnosed with breast cancer. The women in this study had a total of twenty three first-degree relatives with breast cancer; nine mothers, nine sisters, and five daughters. In addition, women also reported six second degree relatives with breast cancer; one grandmother, two aunts, and three cousins. Only four women had a single first-degree relative with breast cancer and no other close relatives diagnosed with cancer.

Ten of the 16 women reported one or more first or second degree relatives diagnosed with cancers other than breast cancer, not including non melanoma skin cancer. These 10 women reported a total of 16 relatives diagnosed with other cancers including three relatives with ovarian cancer, three with pancreatic cancer, two with uterine cancer, and one with colon cancer.

In total, women in the study had 57 first or second degree relatives diagnosed with either breast or other cancers (excluding non melanoma skin cancer), which gives a mean of 3.56 first or second degree relatives diagnosed with breast or other cancers per participant. Ten participants in the present study have family histories of cancer that put them at risk for a hereditary cancer syndrome and would meet evidence-based criteria for a genetic counseling referral and a higher level of surveillance (Hampel, Sweet, Westman, Offit, & Eng, 2004). Two additional participants have family histories of cancer with some of the features of a hereditary cancer syndrome, however, not enough information about their family history was available to determine if they met criteria for a genetic counseling referral. The high

number of women in this sample at potential risk for a hereditary cancer syndrome was not expected. Nearly two thirds of the women in the present study may be at risk for carrying a cancer predisposing gene mutation that would put them at significantly higher risk for breast cancer than the general population. However, only about 5 to 10 percent of breast

Table 2

Characteristics of the Sample (n=16)

Age Ranges	
65-69	5
70-74	4
75-79	3
80 and older	4
Level of Education	
High School graduate	6
1 year of college	3
4 years of college	5
Masters	2
Marital Status	
Currently Married	5
Divorced	4
Widowed	7
Employment Status	
Employed	3
Unemployed	1
Retired	12

Summary of First-degree Relatives With Breast Cancer	
Mother	5
Sister	3
Daughter	2
Mother Sister	3
Mother Daughter	1
Sister Daughter	1
Sister Sister Daughter	1
Breast Self-Exam practices	
two or more times a month	4
monthly	4
every two to three months	1
every six months	2
once a year or less	1
not practicing	4
Clinical Breast Exam Practices	
regular CBE	9
not receiving CBE	7

cancer diagnoses in the general population are thought to be related to hereditary factors, such as carrying a genetic susceptibility gene (Frank & Braverman, 1999; Lea et al., 1998).

The women who participated in this study are at significantly higher risk than the general population for being diagnosed with breast cancer due to both their increased age and their family histories of breast and other cancers, especially those women at risk for a hereditary cancer syndrome that includes breast cancer. For example, three women reported either a daughter or sister diagnosed with ovarian cancer in addition to having a first-degree relative diagnosed with breast cancer putting them at especially high risk for breast ovarian cancer syndrome (Frank et al., 2002).

Mammography Behavior

Most women reported receiving mammography screening, with fourteen women reporting regular mammograms, usually annually. Participants believe mammography is very important because of their family history and sometimes went to great effort to keep track of their mammograms so they did not miss one.

Only two women were not receiving regular mammography. One woman, age 80, reported not receiving a mammogram for over 20 years. Another woman, age 85, reported very infrequent mammography screening reporting five or less mammograms in her lifetime. What these women had in common is that they each had two first-degree relatives diagnosed with breast cancer, one of whom was a daughter who was living, and both women were in their eighties. Their reasons for not having mammograms, however, were different. The 85 year old woman avoided mammograms because the procedure was painful. The 80 year old woman did not find mammography painful, however, she believed breast cancer was primarily a disease of younger women and believed she no longer needed mammograms now that she was older.

The woman who avoided mammography because of pain believed the pain and compression could actually cause breast cancer. “I have it so seldom. I get arguing with them. I say, ‘Every time you guys do this you press so hard, if I don’t have cancer now, I will when you get through’.” When asked about her previous mammography experience she replied “Oh kid, it felt like they were gonna squish it so hard the skin was going to break and then I’d be in a mess… It seems like it makes them feel good to hurt you, you know.” This concern that a painful mammogram could actually cause breast cancer appeared to stem from her belief that her sister’s breast cancer was caused by her sister’s husband pinching her sister’s breast.

> Participant: Well, uh my sister, she said it would come, her husband would come home. He’d grab her by the boob, you know, and pinch it. And uh she said she’d holler at him and all of that because it hurt. So then, I don’t know why she went to the doctor, but anyway she went like in the hospital immediately, and she had cancer in that breast where he kept pinching.

The second woman who was not receiving regular mammography was 80 and had both a mother and daughter diagnosed with breast cancer. This woman believed mammography was important, however she also believed she didn’t need mammograms any more because of her increased age, “I’ve been told that after you reach a certain age it isn’t as important.” She also had faith in her doctor and he hadn’t recommended she have a mammogram, which reinforced her belief that she didn’t need one. “I haven’t had one now in several years now I guess because of my age. Since I'm 80 my doctor hasn't told me to have one for a long time. And I usually follow his suggestions."

Although she was not receiving mammography, she believed it was effective in detecting breast cancer and talked about "the peace of mind that it brings." She used to schedule her own mammograms because she felt strongly they were important but says she doesn't need them anymore now that she is older. She believes breast cancer is primarily a disease of younger women the age of her daughter, who was diagnosed with breast cancer about two years ago in her early fifties.

Breast Self-Exam Behavior

Women reported a lot of variation in their BSE practices, which ranged from two or more times a month to never. Many women had received BSE instruction 20 to 40 years ago and had not received more recent BSE instruction. For example "it's been so long ago, and hard to remember." Another woman reported learning about BSE when her youngest daughter was born, which was 47 years ago. Several women reported that their health care provider assumed they knew how to do BSE so instruction was not offered.

A number of women commented was that they weren't sure what they were looking for or if they were doing BSE correctly. As one woman put it, "I don't know what I was looking for and if I felt it I would know if that was what I was feeling." Another woman is quoted below.

> <u>Participant</u>: I think the problem with that is you can do breast self exams forever and if nothing is wrong with you, you don't find anything. And so you wonder, am I really doing it the right way? And, I mean, you don't want to find anything, but it makes you question whether you're doing it properly. But of course, nothing

shows up, which is what I want, nothing to show up. But, you begin to question. Am I doing this right? Would I, would I know?

BSE was often seen as not very important, especially compared to mammography. For example, "I'm very dependent on my once a year mammogram. I feel I can touch myself forever, but the mammogram is really going to find something obvious like that, plus much more." Although women were faithful about their mammograms, four women reported they did not practice BSE at all, for example, "I just don't do self-exams" or "I know I should do it, but I don't." Another four women practiced BSE monthly, and four more practiced several times a year. Four women also reported BSE more than once a month, ranging from twice a month to several times a week. These women saw themselves as being very diligent. One participant reported practicing BSE "two or three times a week, I don't really keep a calculated list. Just kind of when I'm bathing." It is interesting to note that this woman also reported not receiving either mammography or CBE.

Clinical Breast Exam

Seven of the 16 women in the study reported not receiving a CBE for five years or more. Six of these seven women had family histories o f cancer that put them at risk for hereditary cancer syndrome. When asked if her doctor performed CBE one woman replied "he did it one time when I mentioned it." Another woman, who had three first-degree relatives with breast cancer, responded as follows:

> <u>Participant</u>: Well she hasn't. My girls were surprised that she hadn't uh examined me when I went for my check up. But she did you know tell me to be sure and

> have my mammogram and that she would get the results but she did not give me a breast exam.

The remaining nine women reported regular CBE, usually with their annual exam. Several women also talked about the quality of the clinical breast exam being important. One woman reports:

> Participant: I read this in the newspaper, that doctors are not really, you know your average medical doctor isn't really qualified to do a breast exam, and that uh women really should go to a gynecologist and have a breast exam. And so I clipped that out and I thought, 'I'm going to Dr. [name] about this.' And he said, 'Nah, you don't need that'. And when he examined my breasts, he just goes like this, you know, swish, swish, swish. 'No, there's no lumps.' And you know, he really can't, he really couldn't tell.

It is surprising that so many high risk women in this study reported not receiving CBE. All but one of these women reported having health care providers they saw at least once a year and five of the seven women not receiving CBE were receiving regular mammography.

The Emerging Grounded Theory

Eight major categories emerged from the data analysis: 1) Being aware of risk 2) Always on guard for breast cancer, 3) Beliefs, 4) Keeping faith, 5) Taking charge of health, 6) Having a mammogram, 7) Worry, 8) Peace of mind and assurance (Table 3). Always on guard for breast cancer was chosen as the core category.

The Paradigm Model

The paradigm model is an organizational system which consists of the central phenomena or core category, context, conditions (sets of events or happenings that influence phenomena), actions/processes, and consequences (Strauss & Corbin, 1998). This section will discuss the data according to the components of the paradigm model (Table 4).

The central phenomena or core category in this study is the process of being "always on guard for breast cancer." Always on guard for breast cancer" was chosen as the core category because: it best describes the process women undergo when making mammography decisions, all of the other categories are in some way related to this category, and it facilitates an explanation of how all the categories relate to one another that is logical and explains variation. Having a family history of breast cancer and being an older woman are the contexts for this study since all participants are age 65 or older and have a family history of breast cancer.

Conditions are happenings or events that help explain how and why certain phenomenon occur. Conditions include: being aware of risk, beliefs, and triggering events. Being aware of risk is a condition that affects being always on guard for breast cancer. For example under the condition of being aware of risk women are always on guard for breast cancer which often leads to taking charge of health. Beliefs are conditions that affect taking charge of health.

Table 3

Data Categories

1. Core Category: Always on Guard for Breast Cancer: Women were "always on guard" for signs of breast cancer because breast cancer is an ever present threat in their lives because of their family history of breast cancer.
2. Being Aware of Risk: Women with a family history of breast cancer have an increased awareness of their breast cancer risk. They talk about "being aware" of their risk and how this means they have a greater need for mammograms and other efforts to lower their breast cancer risk.
3. Beliefs: Women talked about beliefs they held that influenced their decisions to have or not have mammography screening. For example, some women believed their breast cancer risk became lower as they got older because it was a disease of younger women. Other women believed that as they got older their breast cancer risk increased.
4. Maintaining Faith: Women had a lot of faith in the ability of mammograms to detect breast cancer and would often ignore negative mammogram information. They also had faith in their health care providers and saw them as credible sources of breast health information.
5. Taking Charge of Health: Women believed strongly in taking charge of their own health by having mammograms, getting health check ups, and exhibiting healthy behaviors as a way to deal with their breast cancer risk by preventing breast cancer or finding it early.

6. Triggering Events: Events that cause women to have some sort of emotional or behavioral response such as worry, peace of mind, or a change in being aware of risk, level of being on guard or taking charge of health behaviors. These events may be positive or negative. Triggering events include: having a family member or friend diagnosed with breast cancer, reaching the age a family member was diagnosed, having a mammogram recall, and discovery of a breast change, reminders, and having a negative mammogram.
7. Worry: Some women worried about getting breast cancer, especially when there was a triggering event such as a family member or friend diagnosed with the disease, they had a mammogram recall, or a breast change was identified. Other women said they would worry about cancer if it happened but that they usually didn't "dwell on it."
8. Peace of Mind and Assurance: Women talked about the "peace of mind" and "assurance" a negative mammogram report gave them meaning that they do not have breast cancer and were "OK for another year."

Table 4

Paradigm Model

Core Category: Always on Guard for Breast Cancer

Context	Conditions	Actions/Processes	Consequences
Having a breast cancer family history	Being aware of risk		Peace of mind
Being an older woman	Beliefs -age increases/decreases breast cancer risk -mammograms will find breast cancer early -believe they will/will not get breast cancer -don't need CBE if MD does not recommend	Taking charge of health -healthy behaviors -physical exam -visit health care provider -mammogram -no mammogram -BSE practices	Assurance
	Triggering events -family/friend diagnosed -age family member diagnosed with cancer. -mammography reminders -mammogram recall -negative mammogram	Maintaining Faith -ignore negative information -believe positive information	Worry

Women who believe that breast cancer risk decreases as they get older are less likely to have mammograms, whereas women who believe breast cancer risk increases as they get older are likely to be very diligent in having annual mammograms. Triggering events are conditions that can lead to taking charge of health, worry, or a change in level of being always on guard for breast cancer. Although most triggering events are perceived as negative, they can also have a positive outcome, such as having a negative mammogram result, which can lead to peace of mind and a high level of assurance.

Actions and processes include: taking charge of health, and maintaining faith. Taking charge of health is what women do to lower their breast cancer risk, find breast cancer early, and therefore guard against breast cancer. Maintaining faith is an active process in which women engage that allows them to believe they are doing all they can to guard against breast cancer and that they do not currently have breast cancer. Women work to maintain faith because it allows them to have peace of mind. Beliefs are one way faith is maintained.

Consequences are peace of mind, assurance and worry. Peace of mind and assurance is what women describe when they have faith that breast cancer is not present. For example, receiving a negative mammogram result is the primary way many women achieve peace of mind and assurance. Women tend to believe positive information they receive about mammography and ignore negative information they receive so they can keep faith in mammography's ability to detect breast cancer. If women believe that mammograms are effective in detecting breast cancer then a negative mammogram result allows them to have peace of mind and a high level of assurance that breast cancer is not present.

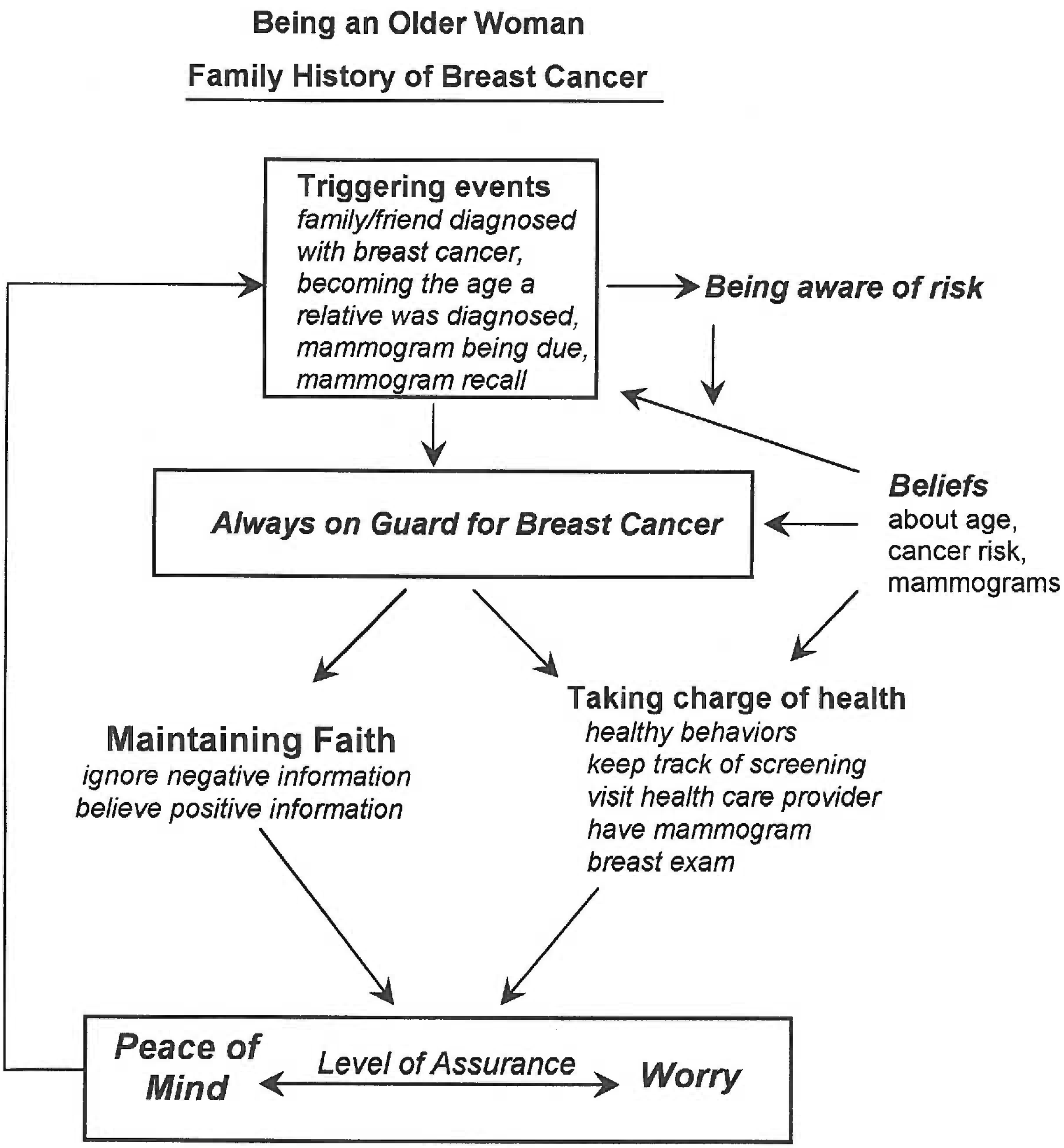
For some women worry is a consequence of triggering events that may signal breast cancer is present. Abnormal mammogram results and breast changes are examples of triggering events that cause some women to worry. Worry interferes with achieving peace of mind.

The Conceptual Model

The conceptual model includes a diagram, description, and explanation of the emerging theory and how the categories relate to one another (Figure 1). The core category is "always on guard for breast cancer", which describes the process women go through when making decisions about mammography and breast cancer screening. With this process women are always on guard for breast cancer, although the level of being on guard varies. How much on guard they are depends on the occurrence of triggering events, how much faith they have in how they are taking charge of their health, and how much they worry. Women's beliefs influence how they are always on guard for breast cancer, how they take charge of their health, and whether or not they have peace of mind or worry. Peace of mind and assurance are achieved when women have faith that they are doing all they can in regard to being always on guard for breast cancer and as a result they believe breast cancer is not present. Figure one is an integrative diagram of this conceptual model, which means it is a graphic representation of the overall process and a synthesis of the relationships among the categories

Figure 1

Integrative Diagram



The starting point in this diagram is a woman on the continuum between peace of mind and worry. There is a triggering event such as a family member being diagnosed with breast cancer, reaching the age at which a family member was diagnosed with cancer, a reminder their mammogram is due, a mammogram recall, having to wait for mammogram results, or the discovery of a breast change. This triggering event leads to an increased awareness of breast cancer risk, especially if there is a lot of breast cancer in the family or if a relative has been recently diagnosed. This being aware of risk leads the person to evaluate what they are doing regarding being always on guard for breast cancer. Women may ask themselves if they are doing everything they can to take charge of their health, especially related to the prevention and early detection of breast cancer. If the triggering event is the diagnosis of a relative, then this may be what leads to the initiation of mammography screening or increased breast cancer screening efforts. If the woman is in a state of worry and the triggering event is having a negative mammogram result, this can allow her to achieve peace of mind and assurance if she has faith that breast cancer is not present.

Here is an example of how an annual mammogram can trigger a higher level of being always on guard by taking charge of health.

> <u>Participant</u>: When it was time to have my annual check up I just would call them and do it myself [schedule her own mammogram] 'cause I'd have to go to the nurse anyway. She'd have to do it. And if I did it, I'd be home with my calendar and make sure that I don't flub up any dates. They seemed okay with that, you know. As long as you don't make too many, you know it has to be only one a year.

For this woman having her annual mammogram due caused her to increase her level of being on guard and take charge of her health by calling and scheduling her own mammogram and keeping track of the date. This is an example of how a woman can go to a higher level of being always on guard for breast cancer without worry.

Women who have faith that they do not have breast cancer go back to peace of mind in this conceptual model. This often results in a lower level of being always on guard for breast cancer. Women who worry sometimes go to go a higher level of being always on guard for breast cancer when certain triggering events occur. Worrying seems to occur when the triggering event poses some threat that breast cancer may be present. An example of this is when a woman has a mammogram recall. This worry seems to be related to fear that they may have breast cancer. Waiting to receive results from a mammogram recall further increases worry about the outcome of the test results. This worry delays them from having enough assurance to return to peace of mind. Here is an example of how a woman regained faith by interpreting the mammography technician's behavior to mean her mammogram was normal.

> Participant: And normally you sit there and you wait and then they come back and say you can get dressed and go home and we'll let you know. Which to me is a great relief because if they hesitate you immediately think there is something the matter.

Here is another example of how a woman regained faith and returned to assurance because the technician reassured her.

> Participant: They called me in again and uh did um an ultrasound. That was pretty scary, even more so. Um, but they explained to me every time that, that uh, you

> know, not to worry, that they err on the side of too much testing, rather than not enough. So that reassured me.

Explanation of Data Categories and Codes

This section describes major categories and codes of data in more detail and includes examples of what participants said that support these major categories and codes. A list of major categories and codes can be found in Table 5.

Always on Guard for Breast Cancer

Always on guard for breast cancer was chosen as the core category because it best represents the process women in the study go through when making decisions about whether or not to have mammograms. The codes under this category are: levels of guard, doing everything I can, and beating the genetic odds.

Women with a family history of breast cancer have a heightened awareness of their breast cancer risk and are "always on guard" for signs of breast cancer because breast cancer as an ever present threat in their lives. Women talked about fear of getting breast cancer, dying of breast cancer or having it and not knowing it. Always on guard encompasses the conditions, actions, processes, and consequences involved when older women with a family history of breast cancer make decisions about whether or not to have mammography. This process, however, has broader application and can also be applied to how women make decisions concerning the prevention and early detection of breast cancer and their management of breast cancer risk.

Table 5

Categories and Codes

1. **Always On Guard for Breast Cancer (Core Category)**

    Levels of guard

    Doing everything I can

    Beating the genetic odds

2. **Being aware of risk**

    Having a family history of cancer

    Becoming aware

    Feeling at risk

    I need it more than the average woman

3. **Beliefs**

    Being older increases breast cancer risk

    Being older decreases breast cancer risk

    Mammograms will find it early

    Mammograms are very important

    Mammograms are better

    Mammograms hurt but are worth it

    Believing in prevention

    Being lucky

    I think I'll get it

    Maybe I won't get it

4. **Maintaining Faith**

    Believing positive information

    Ignoring negative information

    Faith in health care providers

5. **Taking charge of health**

    Getting my own mammogram

    Keeping track of mammograms

    I'd get my mammogram anyway

    Not getting a mammogram

    It's just a routine

    Clinical Breast Exam

        getting it

        not getting it

    Breast Self Exam

        Doing it right

        Remembering to do it

        Not doing it

    Being healthy

    Being optimistic

    Teaching our girls

6. **Triggering Events**

   Family member/friend diagnosed with breast cancer

   Reaching that magic age

   Getting a Recall

   Discovering a breast change

   Reminders

   Having a negative mammogram

7. **Worry**

   Worrying about it

   Not dwelling on it

   Scared to death

   Worrying and waiting

8. **Peace of Mind/ Assurance**

   Assurance

   Peace of mind

   Being OK for another year

   Knowing there's nothing there

Levels of guard

Women vary in how on guard they are for breast cancer. As one woman put it, "you might sometimes be on real rigid, scared, guard and other times you might be lightly on guard." There are triggering events that cause women to be more on guard such as having a mammogram, especially having a mammogram recall, having a friend or family diagnosed with breast cancer, having a breast change discovered by themselves or their health care provider, or reaching the age a close family member was diagnosed with cancer. Below is an example of a triggering event leading to a higher level of being on guard, returning to a lower level of being always on guard, and the cycle repeating itself.

> <u>Participant</u>: And by knowing that you're having this mammiogram [sic] it makes you aware of these breasts and therefore, even though you don't think about them, quote, unquote, you might take the time to examine them. You'll do that before I go in, have the mammogram, and then for a couple of months afterwards. I'm really pretty good about it. Well then it's deep sixed because the mind's on to something else, but see, I'm. You'll see something, a newspaper article, or there'll be a run or something will come up and you'll think then again, that maybe you should do this self-exam and make sure that all is okay and that's what I'm trying, you know.

Doing everything I can

Many women talked about the need to do everything they can to be healthy in an effort to guard against breast cancer. For some women this was primarily focused on breast cancer, however, other women talked about breast cancer along with other health issues, usually in the context of other health problems that were in their family such as heart disease, obesity or diabetes. The woman quoted below has a family history of diabetes and obesity in addition to breast cancer.

> Participant: I just hope that uh maybe it'll be obesity is the next frontier. I don't' know, but on the poster on the wall in my doctor's office, it's one in seven women get breast cancer. That's uh no good. But that doesn't mean you're going to die from it. That just means you might get it. And my sister-in-law had both breasts removed. One because one was cancerous and the other was she was afraid. So she took both breasts. That's pretty radical, I think.
>
> Interviewer: So, how do these things impact the decisions that you make around breast cancer screening?
>
> Participant: Well, it makes me very aware of it, this, for the luck of the draw. Am I that lucky? Can't be what I'm eating and I'm trying desperately [chuckle] to lose weight. That's one thing I can do. But that would also help my blood pressure and heart.

Another participant talks about her efforts to guard against breast cancer through mammograms, diet and exercise.

> Participant: But I had had mammograms before, but somehow I read somewhere after 55 you should have mamms. I can't even remember. And so it was at least 20 years ago, it was about 20 years ago. And I just did it routine, because I've always been health conscious and always done everything preventative, diet and exercise-wise.

Beating the genetic odds

Some women talked about knowing they were at risk due to genetic factors because of their family history of cancer. They also talked about how being always on guard for breast cancer could help them overcome the genetic odds through healthy behaviors.

> Participant: I do have the, the uh potential genetic uh influence and uh I do have the relatives and so I would say that I'm probably have a higher risk than the majority of people….I'm trying to beat the odds by diet and exercise.

Being Aware of Risk

Being aware of risk is about what it means to women to have a family history of breast cancer in terms of their own breast cancer risk. Codes in this category include: having a family history of cancer, becoming aware, feeling at risk, and I need it more than the average woman.

Having a family history

Women talked about having a family history of breast cancer making them more aware of their risk, "You hear about it but until it strikes your own family I guess that's when it becomes important." Having a family history of cancer is significant for the women in the study and they often feel different from other women without this family history. This is especially true for women with a family history of multiple cancers, such as one participant who said "I realize that it doesn't happen to everyone else, it does happen in our family."

Becoming aware

Becoming aware is often the result of a family member being diagnosed with breast cancer.

> Participant: You know as long as it wasn't in our family we didn't think much about it. So when it came to us then we were all more aware. All of us, I have two sisters and a brother and after her diagnoses [mother] then we were all more aware that we should be checked periodically.

Feeling at risk

Women vary in how at risk for breast cancer they feel based on their family history. Some women just don't think about their risk. Other women either feel very at risk or minimize their risk. How at risk they feel does not seem to be related to how much cancer there is in their family. Here is a quote from a woman with two aunts, two sisters, and a daughter with breast cancer who doesn't seem overly concerned about her potential genetic risk and talks about potential environmental factors that may account for the breast cancer.

> Participant: You know, since there, there has been this prominence of cancer as a, a fact in the death of my siblings and relative, I mentioned my aunt. Uh, I probably have a higher risk uh…This might be another factor in this along with environment, uh there might be some inherited factors in this…. Although neither of my parents or grandparents had this, and the siblings that I refer to and the aunt live in an environment totally different than what my parents, grandparents in Italy had.

Here is a different participant talking about feeling at risk, however, she also thinks her efforts to eat less fat may be of benefit.

> Participant: I would say I have a higher risk if you look at family history. Uh, the things that are going for me is that I'm not obese, uh I don't eat a lot of fats, uh but I do have the, the uh potential genetic uh influence and uh I do have the relatives and so I would say that I'm probably have a higher risk than the majority of people.

This participant, however, doesn't feel particularly at risk although she still has her mammograms.

> Participant: I don't worry about it. I don't think that I am at risk right now. I just get the mammograms to be on the safe side. But I've had no problem with my breasts.

I need it more than the average woman

This awareness of breast cancer risk often led to breast cancer screening taking on a new level of importance. Here is how one woman described why mammography is important to her: "I need it more than the average woman, because of this history we just talked about."

Beliefs

Women talked about beliefs they held that influenced their decisions to have or not have mammography screening as well as other behaviors related to taking charge of health and being always on guard for breast cancer. The most common beliefs related to age, mammograms, and whether or not they will get breast cancer. Codes in this category include: being older increases breast cancer risk, being older decreases breast cancer risk, mammograms will find it early, mammograms are very important, mammograms are better, mammograms hurt but are worth it, believing in prevention, being lucky, I think I'll get it, and maybe I won't get it

Beliefs about age and breast cancer risk

Beliefs about age centered on whether or not a woman's breast cancer risk increased or decreased as she became older. Some women in their seventies or eighties believed that their increased age lowered their breast cancer risk because "I've lived this long and I don't have it." They believed either their efforts to stay healthy were successful, they were "lucky" or they for some reason had outlived breast cancer. For example, this participant isn't sure why she hasn't been diagnosed with breast cancer

> Participant: "cause then I've lived to 77 so far. And no big problems, except injuries. Uh, otherwise, may, there could be a lot of them out there that's my age that has breast cancer or younger, and I don't know if it's just a gene in the family or what, 'cause I never got it from my mother, uh from her having it."

Some women believed their breast cancer risk became lower as they got older because it was a disease of younger women. Women who believed that breast cancer was more common in younger women were more likely to have daughters. Here is how one woman describes her breast cancer risk. "I think very slim compared to someone in their 50s or in their 40s"…. Another woman describes her breast cancer risk in relation to her daughter. "This participant

> Participant: You know at my age I, this is the age it isn't likely it really strikes…I thought about it when I was her age" (referring to her daughter who has a breast cancer diagnosis)…. I've never had breast cancer. Mine is not, my mother and

> now my daughter. So I've just, but I haven't had a mammogram now for several years [over 20 years] because somehow I've been told that after you reach a certain age it isn't as important....

In contrast, other women believed that as they got older their breast cancer risk increased. These women tended to be well informed and talked about hearing or reading that age increased breast cancer risk.

> Participant: And as you get older, you begin to realize more and more that your friends are getting it and I heard that one in seven women my age, or maybe even older, would get, get breast cancer. So it's a valuable technology, this mammogram.

Beliefs about mammograms

Women believed strongly that mammograms will find breast cancer early and that their "life may depend on it." Mammography was viewed as very important and "you're stupid not to do it." Women saw mammography as a way to keep breast cancer from surprising them and preventing it from killing them. They believed mammograms were better than either clinical breast exam or breast self exam and was the best technology currently available. For example here is what two women had to say about mammography: "all I know is it's a fantastic technology. It's screening uh breasts for the beginnings of cancer and maybe even farther down the line", and "It's the best thing I can do for right now."

Women talked about the pain of mammography and some women even dreaded having it. In spite of the pain women endured with their mammograms, they dared not have their mammogram because breast cancer might go undetected. Even though mammography was painful, it was worth it. Here is how one person put it. “It hurts for a minute, maybe two minutes. You’ve got a whole year of um reassurance after that, you know. And to me it’s more than worth it.”

Participants believe mammography is very important and often go to a lot of effort to have their annual mammogram. Some women even said they disagreed with their doctor or national recommendations that said mammography was only needed every two years and they would have their annual mammogram anyway. One woman had heard mammography may not be needed in women over age 70 and said she disagreed because she knew too many women over 70 who had been diagnosed with breast cancer. Here is what she had to say.

> Participant: I think it was the Institute of Health, I’m not sure who came out with the lack of a need for mammogram for women under, I believe it was 50, and uh I don’t believe. I, I believe that there are people that need that mammogram and also I believe it was over 70 and I know too many women that have had breast cancer over 70 and I know when your younger 70 seems like you’re old. But now that I’m 70 it’s not old at all. And I think that some people are old at 70, but chronological age is not the best measure of a person’s age. So, but for me personally, no. I will get my mammogram.

Beliefs about whether or not they will get breast cancer

A few women believed they were certain to be diagnosed with breast cancer because of their family history, it was just a matter of when. They talked about waiting for it to happen.

> Participant: And when you have this kind of a background, where it's just a lot of people with cancer, you feel almost like your number is up, you know. You're waiting for the number.

Some women believed they were "lucky" and that was why they had not been diagnosed with breast cancer. Women used different strategies to guard against breast cancer in hopes that they would not get breast cancer. Most women thought what they did to guard against breast cancer would help them not get it. This participant believed her spiritual faith would help to guard against breast cancer and overcome her risk factors.

> Participant: Well, I understand full well that I am at risk, because of two things, you know. The fact that my relatives have so much cancer, at least two things. And because I have all the fibrocystic disease, I, and, you know, because I've had lumps uh removed before. I've been told that that increases your risk for breast cancer. Also I think my diet, you know, that I, I have eaten a high fat diet all my life, you know. A little junk food, you know, and uh that I don't, you know, I'm not. I have been walking more lately. That's more related to fibromyalgia and like that, I need to get moving, my body moving. But I like to read and write and I'm quite sedentary. I understand the more active you are those four things make me think I am at more at risk for breast cancer. ...But then, then I think I just maybe won't get it. You know. Not everybody might get it. ...the lord has blessed me in so many ways and he might just choose to bless me that way too.

Maintaining Faith

Maintaining faith is the process women go through maintain the faith they have in something. Women talked about having faith in mammography, faith in technology, and faith in their health care providers. All of these factors were important considerations in their decision to have or not have a mammogram. Faith in mammography's ability to detect breast cancer early and a strong belief that mammography is the best breast cancer screening technology available was almost universal. This faith in the efficacy of mammography showed up in all interviews regardless of whether or not women were having mammograms. Although faith and beliefs are closely related, faith implies a strong level of confidence even when there is no sound evidence or proof. In this study, the category of "faith" focuses on what women do to maintain their faith and how this allows them to have peace of mind and assurance. Codes for this category include: believing positive information, ignoring negative information, faith in health care providers.

Ignoring negative information and believing positive information

Women's faith in mammography was so strong that information they received about mammography disadvantages was often ignored or dismissed. It is striking to note that occurred even in women where mammography had missed breast cancer in a close relative. Here is an example of where a woman simply ignored evidence that did not support her faith in mammography: "Well, I've read some articles and every now and then there's a study that says that mammography's not as good as they thought it was and I just ignore them." The primary reason women ignore negative information about mammography is so they can achieve peace of mind and maintain their assurance that a negative mammogram means they do not have breast cancer. Here is how one woman put it.

> <u>Participant</u>: Well, you should have peace of mind, more peace of mind, afterwards, like you can just sigh this sigh of relief and say, "Wow, for another year I know

> I'm all right." But, uh, then they, there's this little warning stuff that says uh actually mammograms miss a certain percentage, I've forgotten, but it's too high to suit me. And uh so, then I, I uh think that, well I just, I can't worry about that, I can't. I can't worry about the percentage that doesn't .... I've got too many other things to think about. [laugh] So I just dismiss that.

Faith in health care providers

Women also had a lot of faith in their health care providers and saw them as credible sources of breast health information. Several women reported not receiving CBE because they believed that if they needed a breast exam their health care provider (HCP) would give them one and they had faith their HCP knew what was best. One woman reported not receiving mammograms because her doctor had not recommended them and therefore she must not need them. Women were selective in the health care providers in whom they placed their faith, saying things like "This particular doctor I have a lot of faith in." Participants evaluated the quality of the care they received and would even change health care providers if necessary if they didn't have faith in the provider they had. Changing providers is one way they maintained faith in their provider.

Faith in health care providers also extended to mammography and ultrasound technicians. One strategy women used to achieve faith in a negative mammogram or ultrasound prior to receiving a report was to critically evaluate the behavior of the technician conducting the test. When receiving a mammogram women noticed how soon and how often the technician came back and what they said. Here is an example of how a woman interpreted hesitation.

> Participant: And normally you sit there and you wait and then they come back and say you can get dressed and go home and we'll let you know. Which to me is a great relief because if they hesitate you immediately think there is something the matter.

Here is an example of how a participant maintained faith by carefully watched the technician and evaluated her behavior interpreting what she did not say to mean there was nothing wrong.

> Participant: I don't know, it was in the left breast and there was a spot and I don't know what the spot was, probably was not malignant or they would have told me, and they weren't sure. And so back to the ultrasound, then they were sure, which gave me a great deal of relief and I was conscious during this and *watched her during the procedure* and could see part of um I think the diagnosis was calcium deposits or something like that, and I could see what they were questioning by just watching the ultrasound procedure, which is another thing that makes you feel good....Well you could see, and she would mark uh somehow, you could see a mark where it was suspicious or whatever they were doing and um *the very fact that she didn't go "oops" or "oh" or something of that sort* you know or give you a feeling that there is something wrong made me feel like this was a good feel I guess.

Taking Charge of Health

Women believed strongly in taking charge of their own health by having mammograms, getting health check ups, and exhibiting healthy behaviors as a way to deal with their breast cancer risk. Several women talked about scheduling their own mammograms so they wouldn't be missed. Women believed that taking charge of their health would help lessen their chances of being diagnosed with breast cancer or of dying of the disease. Codes in this category include: getting my own mammogram, keeping track of mammograms, it's just a routine, I'd get my mammogram anyway, not getting a mammogram, clinical breast exam, getting it, not getting it, breast self exam, doing it right, remembering to do it, not doing it, being healthy, being optimistic, and teaching our girls.

Having mammograms

Women were "more aware" of being "at higher risk for breast cancer" risk because of their family history, and for most women this is a major reason they take charge of their health and are diligent in having mammograms. The primary action most women take is to have regular mammograms since mammograms are seen as a way to "see inside" so breast cancer can be detected early and not surprise them. To quote one participant "So I've been having them [mammograms] for twenty-one years, or maybe twenty years. And uh, it was just because there was breast cancer in my family then, that I felt that I needed to keep up on that."

Women talked about depending on their once a year mammogram and mammography being "very important", even "a necessity." Women said things like "I wouldn't go without the mammogram" and I admit I'm very dependent on my once a year mammogram. Cause I feel I can touch myself forever, but the mammogram is really going to find something obvious like that, plus much more." Some women even scheduled their own mammograms. Women were even willing to defy their health care providers, if necessary, to get their mammograms.

Participants often went to extraordinary efforts to have their annual mammograms and sometimes described elaborate systems for keeping track of when they were due. Calendars, marking in red, reminder cards or notes, linking mammograms with recurring events in their lives were all examples of how women kept track of their mammograms. One woman used three calendars to keep track of her mammograms. Here is an example.

> Participant: This is so I keep track. [paper shuffling] And I would put it in a color, not just in ink. There. And I'll take my marking pen here and I'll put a red around that. [goes to circle mammogram in red on the big calendar] That's what I would do for something that important.

Not having mammograms

Not all participants were having regular mammograms, although all participants believed that mammography is effective in detecting breast cancer early. Two women reported not receiving regular mammograms.

One of these two women was 85 and had both a sister and daughter diagnosed with breast cancer. She avoided mammograms because in her experience they were extremely painful and she believed they could actually cause her to have breast cancer. This belief appears to stem from her belief that her sister's breast cancer was caused by her husband "pinching her boob." This woman also believed that she had been through 22 surgeries and she didn't want any more. Her breast cancer risk wasn't something she thought about "at her age." She had received a mammogram in the past year after not having one for years because she was in the hospital for another reason and was talked into having a mammogram.

> Participant: At the hospital, I went in, you know, and signed in and all that and then she said, "Have you had a mammogram?" and I said no, I hadn't had one for years. And uh, she says, "Well, you're going to have to have one." And I'm almost, you know, going to blow up at her. Like, you can't make me have one, you know.

She goes on to say that she finally agreed to have the mammogram after arguing with them when they promised it would not be painful.

> Participant: Well, it was me, I was tellin' her you know that I didn't like to have them and I'm really going to yell loud if she is going to hurt me and this is going to be the last time I'll ever have one if she hurts me, you know. And she says "we don't do that, we take it very easy", so they did. But I let them know I didn't appreciate being hurt.

Although she believes mammograms can be "beneficial to you if they can find, if it's starting, you know", she also believes that painful mammograms can cause cancer "Every time you guys do this you press so hard, if I don't have cancer now, I will when you get through ." She appears to be guarding against breast cancer by not having mammograms. When she finally agreed to a mammogram while in the hospital, this was only after being promised there would be no pain.

The other participant who reported not receiving regular mammograms reported not having had a mammogram in at least 20 years. She also believed mammograms were effective, however, she believed breast cancer was a disease of younger women. Both her daughter and mother had been diagnosed with breast cancer in their forties or fifties. She believed that although she was still at risk, her risk was much lower than it was when she was in her forties and fifties. The way she took charge of her health and guarded against breast cancer was checking her breasts in the shower and watching for any signs and symptoms. She also was careful about her diet. It is also interesting to note that she reported receiving annual physical exams, however, when asked if she had a breast exam she said her doctor hadn't given her one in years so she must not need them.

Breast self exam and clinical breast exam

Both BSE and CBE are strategies used by women to take charge of their health. Since they have been discussed in more depth earlier in this chapter they will be discussed only briefly here. BSE practices were variable ranging from more than once a week to never. Whether or not women practiced BSE seemed to be related both to how confident they felt in their ability to perform the procedure, i.e. "I don't know what I'm feeling for" and how effective they felt BSE was in relation to mammograms. For example: "I don't think it does any good to do self examination. Because by the time you find a lump it's too late, mammograms are better." Women who felt confident in their ability to do BSE tended to practice it and believed both BSE and mammography were important.

Whether or not women received CBE was often, but not always related to whether or not their health provider believed it was important. Most women tended to believe their health care providers knew what was best and if they were not receiving CBE that meant they didn't need them. A couple women, however, said they had to ask for a breast exam to be performed. One woman asked for a breast exam and was told she did not need one, she reported in her second interview that she was considering changing to another doctor because she was losing faith in the one she had.

Being healthy

Women talked about eating a healthy diet, exercise, being optimistic, maintaining a normal weight, and advocating for themselves as strategies they used to take charge of their health in their efforts to guard against breast cancer. Some women compared themselves to people they knew that did not take charge of their health and how they were better off because they had chosen to take care of their health.

> Participant: So that I need to do everything I can to maintain a fairly healthy life style because I have a lot of responsibilities and I don't want to pass these on to my children. So I'll do anything I can to uh, in a preventive mode, to maintain the health. And since my sister had a breast cancer, it isn't only my sister, another sister died of ovarian cancer.

Almost all the women mentioned healthy behaviors they thought would help lower their risk for breast cancer, although not all women practiced these behaviors faithfully. Here is how one woman put it.

> Participant: about taking charge of your health. In theory I really believe in that and I just get these bursts and then I get tired of vegetables or something, I never get tired of fruit so I go for the chocolates and stuff and I don't exercise. So I believe this and they say if you really believe something you will do it and I don't. I just go in bursts and if I'm busy I don't do those things.

Teaching our girls

A number of women talked about the importance of getting their daughters, sisters, and friends to have mammograms and otherwise take care of their breasts. A couple of women asked the interviewer how they could get their daughter or sister to have mammograms. Participants felt their responsibility to take charge of health was not limited to just themselves but that they had a responsibility to remind other in their family of the importance of mammography and caring for their breasts. To quote one woman: "I have certainly talked to my girls and my sister about making sure that they do mammiograms (sic) and, and I poke 'em every now and then to find out if they did."

Optimism

Some women believed optimism lowered their breast cancer risk and they saw themselves as having an advantage over women who were not optimistic. These women tended to be less on guard then women who did not talk about optimism. They tended not to dwell on breast cancer but took charge of their health and focused on being positive. These women were often very active, well informed, and involved in a lot of family and community activities. Here is an example: "But I'd like to think that um I'm a little healthier than a lot of them, because uh I do try to look on the positive side of life."

Triggering Events

Triggering events are those events that may cause women to be more aware of their breast cancer risk, and can lead to a change in level of being on guard and taking charge of health. Triggering events may be perceived by women as undesirable or negative, such as a mammogram recall or having someone being diagnosed with breast cancer. Triggering events can also be positive such as having a negative mammogram result, or even neutral such as reminders. Just because an event occurs does not make it a triggering event. It is when the event leads to some behavioral or emotional response that it becomes a triggering event. The codes in this category include: having a family member or friend diagnosed with breast cancer, reaching that magic age, having a mammogram recall, discovering a breast change, reminders, and having a negative mammogram.

Having a family member or friend diagnosed with breast cancer

Having a close family member diagnosed with breast cancer is often the reason women begin taking charge of their health and having mammograms. This participant describes how someone getting affected breast cancer screening behavior for herself and other family members.

> Participant: But it does, it affects everybody around you when somebody's got breast cancer, or any other type of cancer…. Well, like having your mammogram and that self breast examination. You do, you do that without thinking about it now because before, you know, yeah, you know, you'd do it once in a while.
>
> Interviewer: So it takes on a different level of importance?
>
> Participant: Big level, big difference, yeah, very much so. And with my daughters it made a big difference because they'd never thought about having breast examinations or mammograms or anything else like that. And uh being, you know, just having that in the family.

Here is a participant talking about a friend being diagnosed with breast cancer and the diagnosis being a triggering event for her friend to have a prophylactic mastectomy in the other breast due to family history of breast cancer and for the participant to wonder if she would consider a similar action.

> Participant: Well, a friend of mine in, in uh uh [another state]; they discovered breast cancer, one breast. So they were going to remove it. She had them remove the other one, because she had a family history, no use going through this again, uh

> had it done, I mean, I'm young, I can recover. So if I'm going to do it, do it, you know. In fact I've had a couple of friends that have done that.... I think that was the trigger. I think that was the trigger. Even though I, I have gathered from reading that family history isn't as important as they once thought it was.

Reaching the age a family member was diagnosed

For some women reaching the age at which a family member was diagnosed with breast cancer can be a triggering event, especially for worrying about breast cancer. Here is an example from a woman who is currently the age at which both her mother and grandmother were diagnosed with breast cancer. Although she talks about her distress over being 68, she does not talk about any change in her behavior to alleviate her distress.

> <u>Participant</u>: And my grandmother also died when she was 68. And I'm 68 now.... The closer I got to 68 I, I'm paranoid over being 68....Buy something, well this is the last one I'll ever have to buy and they all know that for years, that I would go when I was 68 and so I guess. My birthday was in January and something came up and I said something about this is my final birthday. It really upset the kids because for years it's been, kind of a running joke that I would be around until 68. But I think I'll get on beyond it.

In contrast this woman talks about doing preventative things.

> <u>Participant</u>: I just think when I'm at that magic age, there's a good, good chance I might get it. But, I'm trying to do all the preventative things. It's not like I've got my head in the sand. I'm trying to do the preventative things.

Having a mammogram recall

The psychological experience of having a mammogram recall or being called back for an ultrasound or other tests is a significant triggering event for many women in the study. Having a mammogram recall was an event that caused women to be more on guard, and led to increased worry, anxiety, and fear in some women. Triggering events, such as a mammogram recall, that could mean breast cancer is present, cause some women to worry. Participants described a mammogram recall as "very scary" and "like somebody hits you in the stomach." Women wanted to hear their mammogram results right away and they wanted results either in writing or by telephone. They did not want to assume that if they did not hear anything that test results were normal. One women changed mammography facilities to one an hour away just so she could have her results right away and not have to wait. Women who worried tended to find recalls traumatic and talked about the emotional experience such as "I was scared to death" rather than what they did to take charge of their health. Women who said they were not worriers talked more matter of fact about recalls focusing on what they did as a result of the recall. Here is an example: "I don't worry about things. I figure, you know, it doesn't do any good to worry so I just, I just, you know, knew I had to go in and have it done and that was it."

Reminders

Women talked about the reminders of breast cancer in the newspaper, on TV, in health magazines, on public radio, and in the news reminding them that breast cancer is an ever present threat in their own lives. Even mammogram reminders can be a triggering event for some women. Sometimes these triggers lead to women increasing their level of guard. They might start doing BSE, practice more healthy behaviors, or schedule their mammogram as a result of these triggers.

> Participant: Well, there's uh, go by a newspaper or a magazine stand and you'll see some health magazine and they'll say something about breast cancer. Or you'll see an ad in the paper about a run for breast cancer or you'll see the little pink uh pins or whatever. Or you'll get uh free uh address labels uh from the cancer society, asking for donations....it kind of triggers stuff... it's one of those things that says, "Okay, it's now the time to do it" [have mammogram].

Having a negative mammogram

Having a negative mammogram report was often a triggering event that allowed women to achieve peace of mind and assurance, especially in women who tended to worry. Here's how one woman talked about a negative mammogram meaning less worry: "there's less worry and peace of mind....Oh yeah, and knowing there's nothing there....big assurance."

> Participant: I feel more comfortable that I've had it done and they said you're okay. And so we go for another year. I think that's the biggest benefit to me. Um, I don't know anything else that it would, that it physically gives me. I mean just assurance that I'm checking up and that I'm probably okay.

It is especially important to women to receive the negative mammogram report in writing, i.e. "I want the card." Receiving the report can be a triggering event. "You know, and, and therefore when I get this letter, it's such a wonderful release for another year."

Worry

Women varied in whether or not they worried about getting breast cancer. Some women tended to be worriers and other women said they were not worriers. Worry tended to be triggered by events in women's lives that may indicated some sort of cancer threat such as a mammogram recall or a breast change. Worry sometimes caused women to increase their level of guard and other times they worried and took no action. Codes for this category include: worrying about it, not dwelling on it, scared to death, and worrying and waiting.

Some women worried about getting breast cancer, especially when there was a triggering event such as a having a family member or friend diagnosed with the disease, having a mammogram recall, or a breast change being identified. Women who tended to worry found mammogram recalls traumatic and were more likely to want results right away. One participant said if she had not received results right away from her recall "I'd have uh been worried the whole time and uh probably would have had trouble sleeping and all of that, yes." Having to wait for test results, especially with a mammogram recall, also caused worry and anxiety in some women.

Other women said they were people that did not tend to worry in general and therefore they did not worry about cancer. They didn't "dwell on it" and "if it happens then I'll deal with it, but I don't focus on it."

Peace of Mind and Assurance

Participants talked about the "assurance" and "peace of mind" conferred by a negative mammogram result and viewed it as meaning they "OK for another year." This assurance was so strong that breast self exam (BSE) and clinical breast exam (CBE) were often seen as not very important. Codes for this category include: assurance, peace of mind, being OK for another year, and knowing there's nothing there.

Having this peace of mind and assurance is very important and allowed women to be less on guard. One participant equates it with relief. "Well, you should have peace of mind, more peace of mind, afterwards, like you can just sigh this sigh of relief and say, 'Wow, for another year I know I'm all right.'" Another participant talks about the assurance that cancer is not present. "Well, it's to uh for peace of mine that there's not a cancer that is lying undetected. That early discovery can lead to uh longer life."

It is not necessary to be having mammograms to achieve peace of mind and assurance, it is only necessary to have faith that breast cancer is not present. For the participant reporting no mammograms for at least 20 years, this assurance came from not having symptoms of breast cancer and also from believing increased age lowered her risk.

Summary of Study Results

Results obtained from this study were described in this chapter. The sample consisted of 16 women between ages 65 to 85 with one or more first-degree blood relatives diagnosed with breast cancer. The core category of data that emerged from this qualitative grounded theory study is "always on guard for breast cancer." Other major categories emerging from the data include: being aware of risk, beliefs, triggering events, taking charge of health, faith, worry, and peace of mind and assurance.

At some level women are "always on guard for breast cancer" (Figure 1). "Being aware of risk" occurs in women because of their family history of breast cancer and leads to being always on guard for breast cancer, since breast cancer is an ever present threat in these women's lives. "Taking charge of health" encompasses the strategies women use to guard against breast cancer by trying to prevent breast cancer, or detect it early and consequently prevent dying from it. Having regular mammograms is the primary strategy women use to take charge of their health and guard against breast cancer. To quote one participant "Well, I think I knew because of my mother that I needed to have a mammogram, so it's never been a decision not to have it. "

"Triggering events" are things that happen in women's lives that often lead to a higher level of being always on guard for breast cancer. Maintaining "faith" is an active process in which women engage to help them feel "peace of mind" and "assurance" that breast cancer is not present. Achieving peace of mind and assurance allows women to be at a lower level of being always on guard for breast cancer. "Beliefs" women have affect how women guard against breast cancer by taking charge of their health and also how they maintain faith. "Worry" is a response some women have to triggering events that interferes with achieving peace of mind.

CHAPTER FIVE

Discussion, Summary, and Implications

The purpose of this study was to generate a beginning grounded theory concerning how older women with a family history of breast cancer make screening mammography decisions. Grounded theory methodology was used to analyze data from interviews with women age 65 and older without a personal history of breast cancer and having one or more first-degree relatives diagnosed with breast cancer. Results indicate that women with a family history of breast cancer have a heightened awareness of their breast cancer risk and are "always on guard for breast cancer" because breast cancer is an ever present threat in their lives. The decision to begin having annual mammograms was often the result of participants being "more aware" of their breast cancer risk after having a family member diagnosed with breast cancer. Having regular mammograms is the primary strategy women use to take charge of their health and guard against breast cancer. Women talked about the peace of mind and assurance they received from having a negative mammogram result. The grounded theory generated from the data describing mammography decision making processes, the categories of data, and the conceptual model were presented and discussed in chapter four.

This chapter discusses interpretations of the study results, implications of the findings in relation to related research, clinical importance of the findings, and recommendations for future research. A study summary concludes this section.

Discussion

Theoretical Implications

Comparison with other grounded theories and qualitative research

Women who have a family history of breast cancer use different mammography decision making processes and have different emotional needs than women without a breast cancer family history. There are some interesting parallels between the present study and another grounded theory of younger women (22-60 years of age) at high risk for breast cancer making decisions about managing their breast cancer risk based on genetic test results (Perry, 2004). The triggering event in Perry's (2004) study was women learning about the their family history of hereditary breast cancer and becoming aware of their own breast cancer risk by undergoing BRCA genetic testing and receiving a positive or uncertain genetic test result. Women went through a process called "seeking peace of mind", which describes how they sought support and made health care decisions aimed at reducing their breast cancer risk to help them feel less vulnerable to breast cancer. Women in both Perry's (2004) study and the present study have a family history of breast cancer and as a consequence feel at risk for breast cancer. Triggering events occur in both studies making the woman aware that having a family history of breast cancer means she is also at risk for breast cancer. In both studies women are seeking peace of mind and making health care decisions they perceive will reduce their breast cancer risk and make them less vulnerable to breast cancer.

Individuals at high risk for cancer may share core experiences related to undergoing lifelong cancer surveillance that are not experienced by individuals at average risk for cancer. Another grounded theory study looked at the impact of lifelong surveillance for thyroid and adrenal cancer in participants diagnosed with MEN2, a rare hereditary cancer syndrome involving abnormal cell growth in endocrine glands (Giarelli, 2003). Persons with MEN2 often undergo prophylactic thyroidectomy or adrenalectomy in addition to lifelong surveillance. In these participants, the threat of cancer is brought to awareness through surveillance or other triggering events such as a self examination, checking for medication supplies, or having a health problem. This brings to the forefront their awareness that cancer is a constant threat to their lives. Individuals are always going through the cycle of attending to the relationship between surveillance events and the threat to health. Finding meaning in the outcomes of surveillance events was the core psychosocial process. Although the core process of Giarelli's (2003) work differs from the present study, the studies are similar in that participants undergo lifelong surveillance, there is awareness that cancer is an ever present threat, and the outcomes of surveillance events have meaning to the participants. These similarities are not dependent on the type of cancer for which the person may be at risk or the age of the participant.

A qualitative descriptive study of women (ages 20 to 69) with a family history of breast cancer looked at coming to terms with being at risk for breast cancer (Chalmers & Thomson, 1996). "Living the breast cancer experience" of the relative led to "developing a risk perception", which was sometimes complicated by emotions such as anxiety. Developing a risk perception involved the women articulating their personal vulnerability to breast cancer. Women often perceived that their risk increased as they approached their relative's age of breast cancer diagnosis. In this phase women would personalize the risk and incorporate other threatening experiences such as having a breast lump. Some women were then able to move to "putting risk in its place" which included becoming an at risk individual and adopting self-care practices aimed at risk reduction and early detection.

In contrast, in a grounded theory study of breast health practices of 12 younger lower risk women (ages 50-64), the core process was "taking charge of health" with the emphasis was on health promotion and disease prevention (Canales & Wilkinson, 2002). Women in Canales's (2002) study were not always on guard for breast cancer nor were they acutely aware of their breast cancer risk. In another study looking at normal risk women's (ages 36 to 83) approach to mammography decision making, the results focus on a continuum of thoughtful consideration to little or no consideration and how much involvement women have in making the decision to have or not have a mammogram (Lewis et al., 1999). There was no focus on risk awareness or family history of breast cancer mentioned as part of the findings in either of theses studies of lower risk women. Mammography was viewed more as a routine health promotion activity without the worry about the outcome or the emotional significance of wanting a negative mammogram to achieve peace of mind found in present study.

Findings from the present study are both similar and different compared to a qualitative study looking at women's beliefs about breast cancer risk and mammography (Silverman et al., 2001). Silverman's (2001) study included 41 women (ages 27 to 84), 12 of whom had a family history of breast cancer. Most women believed that mammography could detect breast cancer early and that cancers were seldom missed. Women also reported the relief from having a normal mammogram outweighed the discomfort and most believed mammography had no downsides. About half the women believed strongly that mammography was important, and the majority reported that if they were to receive an abnormal mammogram they would be fearful of the outcome. In these respects findings are similar to the present study, however, what women took into account regarding the decision appears to be different. In the study by Silverman et al. (2001), when asked what information women thought was important for making decisions about mammography, women focused on knowing the benefits of mammography and what the mammogram was looking for rather than being at risk for breast cancer due to their family history. Since study findings represent both women with and without a family history of breast cancer, whether or not similarities to the present study represent views of women with a family history of breast cancer in contrast to those without is not known. Silverman's (2001) study illustrates the difficulty with interpreting findings when differences between women with and without a family history of breast cancer are not identified.

Findings from the present study appear to be more similar to studies of high risk women, regardless of age, than studies where most women do not have a family history of cancer. These differences support the premise that women with a family history of breast cancer attach more emotional significance to mammography screening and use different mammography decision making processes compared to women without this history.

Comparison with breast cancer screening theories

Much of the work that looking at breast cancer screening in older women is based on adaptations of the Health Belief Model (HBM). The HBM is the most widely used model to explain breast cancer screening and most of this research is by Champion or builds on her work (Champion, 1995; Champion, 1992, 1993; Champion & Scott, 1997; Thomas et al., 1996; Yarbrough & Braden, 2001). According to the HBM, a person's behavior is determined by perception of risk for a certain condition, perceived benefits, and perceived barriers to taking action to decrease this risk (Champion & Miller, 1996; Champion, 1999; Saywell et al., 1999). Mammography studies using the HBM have focused on adherence (Black, Stein, & Loveland-Cherry, 2001; Champion, Foster, & Menon, 1997; Champion, Ray, Heilman, & Springston, 2000; Holm, Frank, & Curtin, 1999; Saywell et al., 1999; Thomas et al., 1996). Results vary in how well the constructs of the health belief model predict mammography behavior, with beliefs and barriers more likely to correlate with mammography screening than perceived susceptibility.

Champion's Susceptibility, Benefits, and Barriers Scale for Mammography Screening is a widely used tool based on constructs in the HBM (Champion, 1995; Champion, 1985). This tool was developed by Champion based on a previous tool she developed for breast self-examination and modified for application to screening mammography (Champion, 1992, 1999). The HBM predicts that women will undergo mammography screening if they perceive themselves susceptible to breast cancer, and believe the benefits of having a mammogram outweigh the barriers to mammography. The HBM, however, does not address decision making processes.

Some findings from the present study that appear to support items from Champion's Susceptibility, Benefits, and Barriers Scale for Mammography Screening. For example, items on the Benefits scale such as "Having a mammogram will help me find breast lumps early", "Having a mammogram will decrease my chances of dying from breast cancer", and "If I get a mammogram and nothing is found, I do not worry as much about breast cancer" are similar to some beliefs women expressed in the present study (Champion, 1995). Women in the present study believe that mammograms will detect breast cancer early and decrease their chances of dying of the disease. Women also talked about having a negative mammogram decreasing worry about breast cancer.

Findings from the present study, however, did not support most of the items on Champion's Barriers scale, such as "Having a mammogram is too painful…takes too much time…is too embarrassing…costs too much money…and would make me worry about breast cancer." Women in the present study believed the pain was worth the benefit, the time was well spent, and mammograms decreased breast cancer worry (Champion, 1995; Champion, 1999). This is not surprising since most women in the present study were receiving mammography screening. Most women in the present study believed they were at increased risk for breast cancer due to their family history and this would lend support to the susceptibility belief component of the HBM. This feeling of susceptibility, however, did not increase CBE or BSE breast cancer screening behaviors.

An integrative research review of 16 studies was conducted looking at the utility of the HBM as a theoretical guide for explaining and predicting breast cancer screening behaviors (Yarbrough & Braden, 2001). While the HBM provided some description of beliefs and behaviors of middle aged women, the model did not appear to have the power to consistently predict breast cancer screening behavior. In addition, the authors concluded the HBM did not reflect the beliefs and practices of those at greatest breast cancer risk, women age 65 and older. The authors recommended further research, especially qualitative, focused on the social meaning of breast cancer and breast cancer screening.

According to the Theory of Care-Seeking (TCS), mammography behavior is explained by the interaction of affect, beliefs, norms, and habits with facilitators (D.

Lauver, 1992; D. Lauver et al., 1997). Affect refers to feelings about a behavior, beliefs to the perceived likelihood of outcomes related to the behavior, norms to the social influences from professionals or family regarding the behavior, habit to one's usual practices related to the behavior, and facilitators to external resources that enable one to engage in the behavior. A study of 178 women (ages 40 to 89) testing the ability of TCS to explain mammography behavior found that variables identified from the theory may not be adequate to explain mammography behavior (D. Lauver et al., 1997). Having a family history of breast cancer and greater beliefs in risk of getting breast cancer were associated with mammography adherence while increased age was associated with decreased adherence which could not be explained by TCS. Another study using the TCS looked at breast cancer screening behaviors in 119 women (ages 51 to 80) (D. R. Lauver et al., 1999). Having a family history of breast cancer was positively associated with BSE but not with mammography screening or CBE. Age and breast cancer risk were not reported as significant for mammography, CBE, or BSE. Mammography and CBE were correlated with each other but not with BSE.

Breast cancer screening behavior in older women with a family history of breast cancer is complex and the HBM and TCS models of screening behavior do not consistently predict breast cancer screening behavior or address how this subgroup of women age 65 and older with a family history of breast cancer make screening mammography decisions. Future research needs to test current breast cancer screening theories in older women with a family history of breast cancer and adapt these theories to this population.

Factors Associated With Mammography Decision Making Processes

Women in the present study talked about what influenced their decision to have a mammogram. Having a mother diagnosed with breast cancer and "having it in my family" were what most strongly influenced women's decisions to have a mammogram. A couple of women talked about having a sister diagnosed with breast cancer being what influenced their decision to have mammograms, however, none of the participants mentioned a daughter's diagnosis influencing their mammography decisions. Three of the five women with daughters diagnosed with breast cancer also had other relatives previously diagnosed with breast cancer so were already aware of their risk. All daughters were diagnosed in their forties or fifties. Although having a daughter diagnosed was a very emotional and sometimes traumatic experience for women, women did not view their daughter's diagnosis as meaning they were at increased risk for breast cancer. Women with daughters diagnosed talked about their daughter's physical and emotional well being, the impact of breast cancer on the daughter's family, and how the diagnosis had affected the mother daughter relationship. To quote two women "I feel kind of shut out....I need to be supportive. But I'm not sure how to do that" and "I thought it should have been me."

Women identified with a sister being diagnosed, for example "it was like it was me", although they did not talk about that event triggering their own screening efforts. All the women in the present study who had sisters diagnosed with breast cancer also had other family members diagnosed with breast and other cancers so they tended to refer to their family history as a whole. Having a breast change discovered prior to age 50 also influenced decisions about mammography screening and was sometimes the initiating event.

Women most often said having a mother diagnosed with breast cancer or having a family history of breast cancer influenced their decision to have mammography: “I knew because of my mother that I needed to have a mammogram, so it’s never been a decision not to have it”, “because it is in my family”, “when I had the lump…I think it all started then”, “to make sure that there is nothing there”, and “for peace of mind.” It is interesting to note that women in the present study did not talk about increased risk due to age as having much if any influence on their decision to have mammography, although a belief that increased age lowers risk was cited as a reason one woman did not have mammography.

A study looking at support needs of women at high risk for breast cancer found women wanted information about personal risk of breast cancer, healthy lifestyle practices, and screening guidelines. Women needed emotional support to help them cope with stress associated with knowing they are at risk and have a family history of breast cancer (Stacey et al., 2002). Focus groups of older women looking at breast cancer screening found family history of cancer was recognized as a major risk factor, however, the contribution of increased age was under recognized (Zapka & Berkowitz, 1992). Under recognition of increased age as a breast risk factor in older women has been found in other studies (Thomas et al., 1996). Clinicians need to be aware of the impact having a mother, sister, or daughter diagnosed with breast cancer has on beliefs about breast cancer risk, emotional support needs associated with being at risk, and how this impacts mammography decisions.

Psychological responses to having mammograms

Results from the present study indicate that older women with a family history of breast cancer have different emotional responses to mammography results, especially when an abnormality is found. Women in the present study who tended to worry found mammogram recalls traumatic and having to wait for test results caused worry and anxiety. This is supported by other studies finding that women with high suspicion or abnormal mammograms experienced mammography related anxiety and worries about breast cancer (Lerman et al., 1991; K. M. Lipkus, Halabi, Strigo, & Rimer, 2000; Lowe, Balanda, Del Mar, & Hawes, 1999).

When worry occurred in the present study, it tended to be in response to some indication that breast cancer may be present such as having a mammogram recall or a breast change being identified. This is consistent with another study looking at younger women at hereditary risk for breast cancer, which found that family history did not predict worry, however, clinical signs of breast cancer were significantly correlated with cancer worry (Loescher, 2003). Worry is complicated because while moderate worry has been associated with increased mammography adherence in women with a family history of breast cancer, mild or severe worry can decrease mammography adherence (Andersen, Smith, Meischke, Bowen, & Urban, 2003; Diefenbach et al., 1999; Lerman & Schwartz, 1993; McCaul et al., 1996).

Women in the present study reported that being able to have follow up mammograms or other tests done the same day, having results right away, and reassurance from mammography staff would all help reduce their worry when a mammogram recall was involved. Women in the present study talked more about emotional distress when there was a mammogram recall than with having a routine mammogram. There may be a continuum of emotional responses to mammography surveillance depending upon women's experiences with breast cancer. In women with a previous cancer diagnosis, cancer related cues, such as follow-up mammography surveillance, can trigger a stress response where this does not occur in women without a cancer diagnosis (Gurevich et al., 2004). It is possible that women with a family history fall somewhere in the middle, although research looking at emotional responses of women with a family history of breast cancer to mammography is limited.

Summary and Implications

Study Limitations

This was a convenience, volunteer sample of Caucasian women. Efforts were made to recruit non Caucasian women, but were not successful. Fourteen of the sixteen women in the study were receiving regular mammography screening. Theoretical sampling was done to recruit women not receiving regular mammography screening, although success was limited. This may be due in part to more women receiving mammography because Medicare covers 80% of the cost for an annual mammogram and secondary insurance often covers the remainder. Another reason may be that women with a strong family history of breast cancer are more aware of their breast cancer risk and therefore more likely to be receiving mammography (Murabito et al., 2001). Women in the present study were fairly well educated. Over half of the women in the study reported at least some college and none had less than a high school education. Most women had multiple first and second degree relatives with breast and other cancers and this may have influenced their mammography decision making processes compared to women with only one first-degree relative with breast cancer.

Limitations related to study recruitment

Community-based recruitment was used rather than recruiting from health care facilities to increase the chances of recruiting women who were not receiving regular mammograms. A limitation of recruiting outside of health care facilities is that medical records cannot be verified to determine the accuracy of self-reported mammogram frequency. Study recruitment relied primarily on recruitment flyers, newsletter advertisements, and short presentations at community events. This type of recruitment requires potential participants to be highly motivated since they need to notice the advertisement and take the initiative to call and ask to participate in the study. Women who are not receiving mammograms may be less motivated to attend community events, pick up flyers, or call and ask to participate in the study. They also may not want to talk about their family history of breast cancer because of their breast cancer fear or may feel guilty for not receiving mammograms. In addition, older women are less likely to participate in research studies compared to younger women (Resnick et al., 2003).

Limitations of self-report

A limitation of the present study is the use of self-report to obtain descriptive data about mammography utilization, whether or not women were receiving CBE, and whether or not they practiced BSE and if so how frequently. Validity of mammography self-report is fairly accurate for reporting a mammogram in the past year, with a sensitivity of 0.93 to 0.98 and specificity of 0.63 to 0.78. Women reliably report whether or not they have ever had a mammogram, however, information about timing and frequency has lower reliability.

Women tend to overestimate time passage for recent events and underestimate time passage for more distant events, a phenomena referred to as “telescoping” (Caplan, Mandelson, & Anderson, 2003; E. S. King, Rimer, Trock, Balshem, & Engstrom, 1990; Norman et al., 2003; Vacek, Mickey, & Worden, 1997). The actual time a mammogram occurred was about three months longer than self-reported time and accuracy of reporting no mammogram was about 98% (Degnan et al., 1992).

While there are studies addressing the validity and reliability of mammography and CBE self-report, validity of BSE self-report is difficult to assess. Although reliability of CBE self-report is similar to mammography (Vacek et al., 1997), no studies addressing the validity of CBE self-report could be located. An advantage of self-report is that accuracy of self-report is fairly high if broad windows are adequate and precise dates are not needed. Since the present study looked at mammography decision making processes and not mammography adherence, precise mammography dates were not necessary. Efforts were made to word questions such in such a way that facilitated information retrieval (Fowler, 2002; Vacek et al., 1997).

Clinical Implications for Health Care Providers

Strategies that promote mammography

Most of the women in the present study reported receiving regular mammography screening. Factors study participants identified as facilitating their decision to have a mammogram include; undergoing a triggering event, having a family history of breast cancer, believing that mammography is able to detect breast cancer early, believing increased age increases breast cancer risk, receiving mammography reminders, and having a health care provider recommend a mammogram or remind them a mammogram is due.

Keeping track of mammograms was an important focus for women in this study. Women who received either a postcard or telephone call reminding them their mammogram was due appreciated that service, i.e. “I’d forget it, if they didn’t send me a card out reminding me.” Women not receiving reminders wanted that service provided. As one woman put it “I wish somebody else would be more detailed about it and remind me.” Research has shown that reminding women that a mammogram is due during a provider visit, by sending a card or letter in the mail, or by telephone call are all associated with increased mammography adherence (Saywell et al., 1999; Taylor et al., 1999).

Health care providers need to be aware that some older women with a family history of breast cancer believe as they get older breast cancer risk becomes lower and they may no longer need breast cancer screening, especially if their relative was diagnosed with breast cancer at a younger age. Women need to be informed that their breast cancer risk continues to increase as they become older due to both age and having a family history of breast cancer.

Support needs of high risk older women

Many high risk women in the present study reported experiencing worry when having to wait for mammography results and when having a mammography recall. Women reported that receiving test results the same day and having a mammogram at a facility where any additional mammogram views or follow up tests can also be done the same day helps alleviate worry. Women with a family history of breast cancer who are called back for additional mammogram views or other follow up tests need emotional support.

Findings for the present study also have implications for mammography and ultrasound technicians. Being called back for additional mammogram views or other follow up tests, such as breast ultrasound, is a significant emotional experience for the women in this study. They often paid close attention to the technician's verbal and non verbal behavior, looking for clues as to the outcomes of their mammogram or ultrasound results. Although mammography and ultrasound technicians do not read the mammogram or ultrasound tests, women perceive them as knowing whether or not these tests were normal. Dissemination of results from the present study to mammography technicians may help them better understand and support women with a family history of breast cancer undergoing mammography.

Family history and potential genetic susceptibility to breast cancer

The women who participated in the present study are at significantly higher risk than the general population for being diagnosed with breast cancer due to both their increased age and their family histories of breast and other cancers. Ten of the 16 women are at potential risk for carrying a genetic susceptibility gene associated with a hereditary cancer syndrome such as breast ovarian cancer syndrome, which carries a lifetime breast cancer risk of 60 to 85% and a lifetime ovarian cancer risk of 15 and 40% (Hampel et al., 2004; Wooster & Weber, 2004). Two women are also at risk for Hereditary Non Polyposis Colon Cancer (HNPCC), which is associated with a high risk for colon and endometrial cancers. Although all these women met criteria for cancer risk assessment, only one of the ten women reported being referred for cancer risk assessment and genetic counseling. Clinicians need to obtain a family history of cancer and refer women with a strong family history of cancer for cancer risk assessment and genetic counseling and testing if indicated.

Current cancer screening recommendations for breast, ovarian, colon and uterine cancers are stratified based on level of risk, and screening recommendations for high risk women who carry a cancer predisposing mutation are different than for women who do not carry a cancer predisposing mutation (ACS, 2005; R. A. Smith et al., 2005). Women are categorized as high risk for breast cancer if they are known to carry a breast cancer predisposing mutation or if they have not been tested and have a family history suggestive of such a mutation. Women at high risk for breast cancer may benefit from breast ultrasound, magnetic resonance imaging, or more frequent screening (R. A. Smith et al., 2003). Women who carry a BRCA mutation are also recommended to have ovarian cancer screening (Burke et al., 1997). For example, the three women in the study who reported either a daughter or sister diagnosed with ovarian cancer in addition to having a first-degree relative diagnosed with breast cancer may need to be screened for ovarian cancer.

It was not expected that so many women volunteering for the study would be at potential risk for carrying a cancer predisposing mutation. One possible explanation is that these high risk women may have been more likely to notice the recruitment flyer due to their "being always aware of risk." Several women stated that the words "family history of breast cancer" caught their attention and they wanted to help with the research because of the cancer in their family. Based on self-reported family history and breast cancer screening behaviors, it appears that a number of women participating in the present study may be in the high risk category for breast and possibly other cancers such as ovarian, uterine, or colon and if so, may not be receiving adequate screening.

Clinical breast exam

Almost half of the women in the study reported their health care providers were not performing CBE, six of whom are at potential risk for a hereditary cancer syndrome associated with a high breast cancer risk. Based on women's reports, health care providers may not be giving adequate attention to taking a thorough family history, assessing breast cancer risk factors, or conducting a through CBE when it is provided. CBE standards changed with the American Cancer Society's 2004 publication of new comprehensive clinical breast exam guidelines and standards (McDonald et al., 2004; Saslow et al., 2004). These new guidelines include taking a family history, assessing breast cancer risk factors, and annual CBE prior to mammography in post menopausal women. These standards also include detailed guidelines for how CBE is to be performed using the vertical strip method. Studies are presented demonstrating that many health care providers lack adequate training in performance of CBE, and that training health care providers in CBE performance improves CBE efficacy (McDonald et al., 2004). Health care providers providing breast cancer screening for older women need to take a family history of cancer and provide a thorough breast exam using the vertical strip method (Saslow et al., 2004).

Breast self exam

BSE practice varied greatly among women in the study and they often talked about not knowing if they were doing it correctly or if they would be able to recognize an abnormality in their breasts if it was present. Health care providers often assumed women knew how to do BSE correctly and did not offer instruction. A number of women reported BSE instruction was given over 20 years ago and had not been updated. For example one woman said "I think my, one of my uh doctors, my obstetrician…taught me." Another woman reported she learned BSE "it was when my youngest daughter was a baby, which would, she's 47. So it would have probably been 47 years ago."

Although studies have not found BSE to decrease breast cancer mortality, these studies have not taken into account differences in BSE proficiency and search patterns. BSE training using the vertical strip method improves BSE proficiency (Leight, Deiriggi, Hursh, Miller, & Leight, 2000). A meta-analysis of 20 BSE studies concluding that due to methodological problems more research needed to be done to determine whether or not BSE impacted breast cancer mortality (Ku, 2001). Older high risk women need to be offered BSE instruction using the vertical strip method with the opportunity to practice on breast models. Future research needs to measure lump detection rates, feelings of competency, and psychosocial outcomes of older high risk women after receiving BSE instruction using the vertical strip method.

Implications for Future Research

Few studies have examined the contribution of emotions and emotional regulation to cancer screening behavior. Research on the relationship of worry, fear, and anxiety in relation to breast cancer screening have often led to conflicting results and have lacked a clear theoretical framework in which to consider them (Consedine, Magai, & Neugut, 2004). Because emotions such as fear, anxiety and worry have well documented motivational functions, they are likely to have a powerful influence on screening behavior. Research tends to assume the relationship between these emotion variables and screening behavior is linear, where there is evidence that the relationship is more complex (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut, 2004; Consedine, Magai, & Neugut, 2004). Theoretically based research using reliable and valid measurement tools is needed to more systematically examine the relationships between fear, anxiety, worry and breast cancer screening behavior.

Having a mammogram, especially a mammogram recall, is a significant emotional experience for the many of the women in the present study, however, research addressing the emotional experience of mammography is limited. Mammography research looking at psychological factors such as worry tend to address whether or not these factors correlate with increased or decreased mammography behavior and not the psychological needs of women undergoing mammography (Andersen et al., 2003; Diefenbach et al., 1999; McCaul et al., 1996). In 1991 Lerman identified that the psychological consequences of screening mammograms had been neglected and that research was needed to test interventions aimed at promoting psychological adjustment among women with abnormal results (Lerman et al., 1991). Future research is needed to more clearly identify the emotional needs of high risk women receiving mammography and what interventions may be helpful in alleviating this emotional distress. Studies are needed to identify support needs for women undergoing mammography recall, the impact of delay in receiving mammography results, and psychological outcomes in women who receive care in centers where follow up tests can be done the same day compared to having to come back at a later date. Research needs to address how to adequately instruct older women in BSE so those who practice BSE can feel more competent.

There is some indication both in the present study and in the literature that increased age may be under recognized as a breast cancer risk factor in older women. Research needs to explore older women's beliefs about the relationship between increased age and cancer risk and how this translates into breast cancer screening behavior. Findings from the present study need to be compared to a larger sample of older women who do not undergo mammography screening and also to different ethnic groups to find out how their mammography decision making may be similar or different. Younger women with a family history of breast cancer also need to be studied since age appears to have less influence on mammography decision making than having a family history of breast cancer. It would also be interesting to study women and men with a family history of other cancers, such as colon cancer, to find out if this theory has application in the context of other cancers.

Study Summary

Purpose

The present study's purpose is to describe and explain how older women with a family history of breast cancer make screening mammography decisions and to generate a beginning grounded theory describing these decision making processes.

Background

Older women with a family history of breast cancer are at increased breast cancer risk due to both increased age and family history. In spite of known mammography benefits and Medicare coverage for mammograms, older women with a family history of breast cancer still receive inadequate mammography screening (Lane et al., 2000) (Roetzheim et al., 1996). Although much research has focused on factors associated with whether or not women have mammograms, older women with a family history of breast cancer are under represented, and few studies have addressed how these women make decisions about whether or not to have a mammogram.

Methodology and Sample

Grounded theory method was used in this research to generate a beginning grounded theory concerning how older women with a family history of breast cancer make screening mammography decisions. Conditions, context, and meanings that influence the screening mammography decision making processes in these women were identified. Qualitative data for this constructivist grounded theory study was collected using open-ended semi-structured interview questions. Participant check, peer debriefing and audit trail were used to verify data accuracy. Sixteen women ages 67 to 85 with one to three first-degree relatives diagnosed with breast cancer participated in the study. Twelve of these women had multiple relatives diagnosed with breast and other cancers.

Results

Eight major categories emerged from the data analysis: 1) Being aware of risk 2) Always on guard for breast cancer, 3) Beliefs, 4) Keeping faith, 5) Taking charge of health, 6) Having a mammogram, 7) Worry, 8) Peace of mind and assurance (table 2).

The core category is "always on guard for breast cancer", which describes the process women in the study go through when making decisions about mammography and breast cancer screening. Women with a family history of breast cancer have a heightened awareness of their breast cancer risk and are "always on guard for breast cancer" because breast cancer is an ever present threat in their lives. The decision to begin having annual mammograms is often the result of participants being "more aware" of their breast cancer risk after having a family member diagnosed with breast cancer. How much on guard women are depends on the occurrence of triggering events, how much faith they have in how they are taking charge of their health, and how much they worry. How women take charge of their health is influenced by their beliefs. Peace of mind is achieved when women have faith that they are doing all they can in regard to being always on guard for breast cancer and as a result they believe breast cancer is not present. Some women believe increased age lowers breast cancer risk and these women sometimes decide not to have mammograms because they think they no longer need them.

Study implications

Women with a family history of breast cancer attach more emotional significance to mammography screening and use different mammography decision making processes than women without this history. Women were not receiving adequate CBE, did not feel competent performing BSE and were not being referred for genetics services when hereditary cancer risk factors were present. Health care providers need to obtain a family history of cancer, provide annual CBE using the vertical strip method, offer BSE instruction, and follow recommended guidelines for referral of women with a family history of cancer for cancer risk assessment and genetic testing (National Comprehensive Cancer Network, 2002).

Future research needs to apply this grounded theory to women with a broader ethnic and socioeconomic diversity and also to persons with a family history of other cancers such as colon cancer. Research also needs to examine the negative emotional consequences of mammography recalls such as worry, anxiety, and cancer fear in older women with a family history of breast cancer and to test interventions to reduce the negative outcomes associated with mammography recalls such as providing same day follow up tests, shortening the time to it takes for a woman to receive test results, and providing emotional support.

Findings from the present study can inform health care providers regarding the worry, anxiety and fear older women with a family history of breast cancer often experience with a mammography recall, especially when there is a delay in receiving test results. Health care providers need to schedule follow up mammograms and tests such as ultrasound or breast biopsy as soon as possible, minimize the time it takes to report test results, and provide emotional support to women during this process.

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APPENDIX

Consent form

Interview guide

Demographic questionnaire

IRB Approval Communication

IRB# 8115

Protocol Approval Date: February 6, 2004

OREGON HEALTH & SCIENCE UNIVERSITY
Research Consent and Authorization Form

SUBJECT NAME: ______________________ DATE: ______________

TITLE: Mammography Decision Making in Older Women With a Family History of Breast Cancer

PRINCIPAL INVESTIGATOR:	Lillian M. Nail, RN, CNS, PhD	(503)494-5618
CO-INVESTIGATORS:	Karen E. Greco, RN, MN, ANP	(503)799-9941
	Judith Kendall, RN, PhD	(503)494-3573
	Deb Messecar, RN, MPH, PhD	(503)494-3890

SPONSOR: John A. Hartford Foundation Building Academic Geriatric Nursing Capacity Pre Doctoral Scholarship.

INTRODUCTION:
You have been invited to participate in this research study because you are female, age 65 or older, and have a parent, sibling (sister or brother), or child who has been diagnosed with breast cancer.

WHY IS THIS STUDY BEING DONE?
The purpose of this study is to better understand how older women with a family history of breast cancer make decisions concerning breast cancer screening.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?
As many as 30 people will take part in this study, which will be conducted through Oregon Health & Science University.

WHAT IS INVOLVED IN THIS STUDY?
You will be interviewed one to three times by the investigator, an experienced nurse practitioner. You will be asked questions concerning how you make decisions about breast cancer screening. You may only be interviewed one time or you may be asked if you would be willing to be interviewed a second or third time. Each interview will take about one to two hours. You will be asked for your permission to tape record the interview. You will be identified on the tape only by number to protect your privacy. After the interview the tape will be transcribed (typed up). Only persons listed in the consent form as authorized to have access to information from the study will have access to information from the tape

recording. All information will be kept in a locked file cabinet or on the computer in password protected files.

HOW LONG WILL I BE IN THE STUDY?

You will be in the study from one to twelve months. You may only be interviewed one time or you may be asked if you would be willing to be interviewed a second or third time. Those participants who are invited for a second interview will be invited because the investigator has additional questions about information from the first interview or because the investigator wants feedback from you about whether or not findings from the study make sense to you.

PROCEDURES:

RISKS AND DISCOMFORTS:

It is possible that you could become tired from taking part in the interview. Some of the questions may seem personal, upset you, or cause you to recall some unpleasant experiences you have had in the past. You may refuse to answer any of the questions that you do not wish to answer. If you become so upset by any of the questions that you appear to need counseling, you will be referred to an appropriate counselor.

BENEFITS:

You may or may not personally benefit from being in this study. However, by serving as a subject, you may help us learn how to benefit patients in the future.

ALTERNATIVES:

You may choose not to be in this study. You may also drop out of the study at any time if you wish. Taking part or not taking part in this study will not affect any of your medical treatment in any way.

CONFIDENTIALITY AND PRIVACY OF YOUR PROTECTED HEALTH INFORMATION:

If you sign this form, you are agreeing that OHSU may use and disclose protected health information collected and created in this research study. The specific health information and purpose of each use and disclosure are described in the paragraph below:

Information collected in this study will include information you provide in the interview related to how you make decisions concerning breast cancer screening. Information will also be collected from questions we ask you about age, your family history of breast cancer, type of health insurance, your race, education, marital status, and any major health problems you may have. This information will be collected to help us learn more about how older women with a family history of breast cancer make breast health decisions. This information will also help us analyze the research results from this study.

The persons who are authorized to use and disclose this information are: All investigators listed on page one of the Research Consent and Authorization Form, others at OHSU who are participating in the conduct of this research protocol, the OHSU Institutional Review Board, the OHSU Cancer Institute, and federal or other governmental agencies responsible for research oversight.

While this study is still in progress, you may not be given access to medical information about you that is related to the study. After the study is completed and the results have been analyzed, you will be permitted access to any medical information collected about you in the study. If this study has not collected any medical information about you, you will be advised of that. We may continue to use and disclose protected health information that we collect from you in this study until the study is completed.

You have the right to revoke this authorization and can withdraw your permission for us to use your information for this research by sending a written request to the Principal Investigator listed on page one of the Consent and Authorization Form. If you do send a letter to the Principal Investigator, the use and disclosure of your protected health information will stop as of the date he/she receives your request. However, the Principal Investigator is allowed to use information collected before the date of the letter or collected in good faith before your letter arrives. Revoking this authorization will not affect your health care or your relationship with OHSU.

WHAT ARE THE COSTS FOR PARTICIPATING IN THIS STUDY?

There are no costs to you for taking part in this study. You will not be paid for your participation.

LIABILITY:

The investigator does not offer to pay for medical expenses for injuries unrelated to the study protocol or that are caused by any disease or condition you may have. The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury and damage from this research project through the fault of the University, its officers or employees, you have the right to bring legal action against the University to recover the damage done to you subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived your legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the OHSU Research Integrity Office at (503) 494-7887.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.

Karen E. Greco at (503) 799-9941 has offered to answer any questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the OHSU Research Integrity Office at (503) 494-7887.

Your consent to participate in this study and your authorization to let us use and disclose your protected health information are voluntary. You may refuse to sign this consent and authorization form. If you refuse to sign this consent and authorization form, your health care and relationship with OHSU will not be affected, however, you will not be able to enter this research study.

<u>SIGNATURES</u>:

Your signature below indicates that you have read this entire form and that you agree to be in this study. You will be given a copy of this consent and authorization form.

____

Subject's signature Date

<u>CONSENT TO HAVE THE INTERVIEW(S) TAPE RECORDED</u>:

Your signature below indicates that you agree to have your interview(s) tape recorded.

____

Subject's signature Date

____

Subject's printed name

Karen E. Greco, RN, MN, ANP

____

Investigator's signature Investigator's printed name

Mammography Decision Making in Older Women With a Family History of Breast Cancer

Semi Structured Interview Guide, Page One

Karen Greco, RN, MN, ANP

THE FOLLOWING QUESTIONS ARE RELATED TO AIM ONE

Identify antecedent, concurrent, and consequent factors associated with the mammography decision-making processes in older women with a family history of breast cancer.

Tell me about your decision to have (or not have) a mammogram?

How did you make the decision to have a mammogram?

What things were important to you in making the decision to have a mammogram?
(probe) Why were these things important?

What do you recall about your experience of having a mammogram?
(probe) What was it like to have a mammogram?
What aspects of it were difficult; what aspects were not difficult?

What are your sources of information about mammography?
(probe) What information did you receive? What do you know about mammography?
How did that information influence your decision to have/not have a mammogram?
Anything else? Can you tell me more? Can you explain why?

Tell me what you think/believe the benefits are to having a mammogram?
(probe) How does thinking/believing that mammography is beneficial influence your decision to have/not have a mammogram?

Tell me what you think/believe to be the downside to having a mammogram?
(probe) Did this influence your decision to have/not have a mammogram? How?

Tell me about anything you may have read or heard about that made you think you did or did not need a mammogram?
(probe) How does thinking/believing that mammography is beneficial influence your decision to have/not have a mammogram?

Mammography Decision Making in Older Women With a Family History of Breast Cancer

Semi Structured Interview Guide, Page Two

Karen Greco, RN, MN, ANP

THE FOLLOWING QUESTIONS ARE RELATED TO AIM TWO
Describe the conditions, context, and meanings influencing screening mammography decision making in older women with a family history of breast cancer.

Tell me about how your age may have influenced your decision to have/not have a mammogram?
(probe) Tell me about anything that might be different now about how you decided to have/not have a mammogram compared to when you were younger?

How would you describe your breast cancer risk compared to other women your age?
(probe) Would you describe your risk as higher, lower, or about the same as other woman your age?

Tell me about how your breast cancer risk may have influenced your decision to have/not have a mammogram?

Tell me about having a family history of breast cancer?
(probe) Tell me about how having a family history of breast cancer has influenced your decision to have (or not have) a mammogram?

You mentioned that your health care provider recommended/did not recommend you have a mammogram. Tell me about how that may have influenced your decision to have/not have a mammogram?

Is there anything else you would like to tell me that we haven't talked about?

Demographic Questionnaire

Today's Date___________________

Participant number ______________

1. What is your age?_______________

2. What best describes your ethnicity?
   - ☐ Hispanic or Latino
   - ☐ not Hispanic or Latino
   - ☐ Unknown

3. What best describes your race?
   - ☐ White or Caucasian
   - ☐ Black or African American
   - ☐ Asian
   - ☐ Native Hawaiian or other Pacific Islander
   - ☐ American Indian or Alaskan Native
   - ☐ More than one race
   - ☐ Unknown
   - Other ____

4. What is the highest level of education you have completed?
   - ☐ 8th Grade or less
   - ☐ Partial High School
   - ☐ High School graduate
   - ☐ College 4 years
   - ☐ 2 year College or technical school
   - ☐ Masters Degree
   - ☐ Doctorate
   - Other ____

5. What best describes your current marital status?
   - ☐ Currently Married or in a long term partnered relationship
   - ☐ Single, never married
   - ☐ Divorced
   - ☐ Widowed

6. What is your current employment status?
   - ☐ Employed, what kind of work do you do___________________________
   - ☐ Unemployed
   - ☐ Retired, what kind of work did you do_____________________________

7. What is your situation?
   - ☐ Live with someone__________________________
   - ☐ Live alone
   - ☐ Living situation with services_____________________________

7. Has anyone in your family has been diagnosed with breast cancer?

☐ Mother age at diagnosis________ living ☐ yes ☐ no
☐ Father age at diagnosis________ living ☐ yes ☐ no
☐ Sister age at diagnosis________ living ☐ yes ☐ no
☐ Daughter age at diagnosis________ living ☐ yes ☐ no
☐ Maternal Aunt age at diagnosis________ living ☐ yes ☐ no
☐ Paternal Aunt age at diagnosis________ living ☐ yes ☐ no
☐ Maternal grandmother age at diagnosis________ living ☐ yes ☐ no
☐ Paternal grandmother age at diagnosis________ living ☐ yes ☐ no
Other________________ age at diagnosis________ living ☐ yes ☐ no

8. Have you or anyone in your family been diagnosed with cancer?

☐ Yes
☐ No

If yes, what type of cancer did they have and what was their relationship to you?____

9. Have you ever had a mammogram?

☐ Yes
☐ No *if no, go to question 11*

How long ago was that?

☐ in the past 3 months
☐ in the past 6 months
☐ in the past year
☐ in the past two years
☐ over two years ago
other ____

10. How many mammograms have you had in the past year?

☐ none
☐ 1
☐ 2
☐ 3 or more

11. Do you practice Breast Self Exam?

☐ Yes
☐ No

12. About how often do you perform Breast Self Exam?

☐ monthly
☐ every other month
☐ every three months
☐ every six months
☐ once a year or less
☐ never

13. Do you have a health care provider? (A health care provider can be a physician, nurse practitioner, physician's assistant, naturopath or other health practitioner you visit for your health care.)

☐ Yes
☐ No *if no, go to question 17*

If yes, what kind of health care provider do you have?

☐ MD
☐ nurse practitioner
☐ physician's assistant
☐ naturopath
other_________________

14. How many times in the last year do you recall visiting your health care provider?

☐ none
☐ once
☐ twice
☐ 3 or more times

15. Did your health care provider recommend you have a mammogram?

☐ Yes
☐ No

16. Has your health care provider ever performed a breast exam?

☐ Yes
☐ No

How long ago was that? _____________________________

17. Please list any health problems you have.____

____

18. Do you have any health insurance?

☐ Yes
☐ No

If yes, please check all that apply

☐ Medicare
☐ supplemental health insurance
☐ Oregon Health Plan
other____

OREGON HEALTH & SCIENCE UNIVERSITY
Research Integrity Office, L106-RI (503) 494-7887

MEMO

Date: February 6, 2004

To: *Lillian Nail ANP SN-ORD*
Karen Greco SON-ADM

FEB - 6 2004

From: Gary T. Chiodo, DMD, Chair Institutional Review Board, L106-RI
Susan Hansen, MD, MPH, Co-Chair, Institutional Review Board, L106-RI
Charlotte Shupert, PhD, Manager, Research Integrity Office, L106-RI

Subject: *8115, EXP*
Mammography decision making in older women with a family history of breast cancer

Initial Study Review
Protocol/Consent Form Approval

This study is currently approved for 30 subjects .

We received your response to the IRB requirement(s) on 2/5/2004 .

Your protocol is approved for one year effective FEB - 6 2004 **.**

Your combined consent/authorization form is approved by the IRB effective FEB - 6 2004 **.**

You may use only copies of the attached approved consent/authorization form for the informed consent process. Please write the date of annual protocol approval in the upper right hand corner on the first page of the consent/authorization form. If you submit a revised consent/authorization form for approval during the coming year, please type the annual protocol approval date on the first page when revising the form.

This study met the criteria for EXPEDITED IRB review based on Category # 7[1].

The requirement to obtain informed consent and HIPAA authorization has been waived or its elements have been altered in accordance with 45CFR46.116(d)(1-4) and 45CFR164.512(i)(1)(i) for the telephone screening portion of this study. This memo confirms:

- That the research involves no more than minimal risk to the subjects;
- That the waiver will not adversely affect the rights and welfare of the subjects;
- That the research could not practicably be conducted without the waiver;
- That the research could not practicably be conducted without access to and use of the PHI;
- That the use or disclosure of the PHI involves no more than minimal risk to the privacy of the subjects as a result of:
  An adequate plan to protect the PHI from improper use and disclosure;
  An adequate plan to destroy any identifiers contained in the PHI at the earliest opportunity consistent with the research;
  Adequate written assurances that the PHI will not be reused or re-disclosed to any other person or entity, except as required by law, for authorized oversight of the research study, or for other research for which the use or disclosure of PHI would be permitted; and
  Whenever appropriate, the subjects will be provided with additional pertinent information after participation.

This waiver of consent and authorization applies only to the PHI for which use or access has been requested and described in the attached request for waiver.