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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING

Breast Health and Mammography Screening in Older Women

by

Martha A. Ibarra, MSN, RN, ANP

A dissertation presented to the
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
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requirements for the degree
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Dissertation Committee

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Abstract

Age-related health disparities in breast cancer screening are a public health concern. From 2002 to 2006, the median age for newly diagnosed cases of breast cancer was 61 years and the median age for breast cancer mortality was 68 years of age (Surveillance Epidemiology and End Results [SEER], 2009). Mammography is the best available screening tool for breast cancer detection (Susan G. Komen Foundation, 2008). The Centers for Medicare and Medicaid Services (CMS, 2006) reported that only about half of older women who are eligible for mammograms through Medicare obtain a mammogram every two years.

The literature identifies psychosocial barriers, including a lack of breast cancer knowledge and cancer fatalism, as independent predictors of mammography participation among older women. The purpose of this quasi-experimental study was to determine the effects of a breast health awareness program on older women's knowledge of and fatalistic attitudes toward breast cancer and breast cancer screening and on their participation in mammography screening.

Sixty women over 65 years of age will be recruited from 4 senior nutrition programs located in underserved areas of San Diego County to participate in a breast health awareness program. Data will be collected using a demographic questionnaire, pre and postintervention revised Powe Fatalism Inventory, and a breast health knowledge

questionnaire. Descriptive statistics will be used to analyze the relationship of fatalism to breast cancer knowledge and the relationships of knowledge and fatalism to mammography participation.

The potential impact of the intervention will lie in earlier diagnosis of breast cancer disease in older women through improved screening participation, resulting in decreased breast cancer mortality among older women in San Diego County.

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DEDICATION

First and foremost, I would like to thank God for giving me the gift of my doctoral education and the calling to be a nurse. His love and strength has carried me throughout my entire nursing education, and it is through Him only that I successfully overcame many challenging barriers. Without his presence this dissertation would have not been possible.

A very special dedication to my daughter Rayne. I am forever grateful God made you my child, for you have been my biggest inspiration. What once seemed to be an impossible mission, is now a true reality as together we have broken a "Cycle." It means the world to me to have shared this special journey with you, and my hope is that it will always remind you that "through Him all things are possible." Thank you for your patience and your unconditional love. You are "MY GREATEST LOVE OF ALL."

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Introduction

Decreased participation in mammography screening among older women has been linked to advanced breast cancer disease at time of diagnosis. Both lack of knowledge and fatalistic perceptions of breast cancer have been reported in the literature review as barriers to mammography screening among older women. The focus of this interventional study is to reduce age-related disparities in early breast cancer detection among underserved older women. The study addresses barriers to mammography screening in this population, including knowledge of and fatalistic attitudes towards breast cancer screening.

My previous experience as an oncology nurse and my current role as a nurse practitioner working with underserved populations in community health have both led me to identify the need for addressing barriers to early cancer detection most commonly found in underserved communities.

It is my hope that this study will potentially have an impact on earlier diagnosis of breast cancer in older women through improved screening participation. Earlier diagnosis will permit earlier treatment at less personal and societal cost and reduce breast cancer mortality among older women in San Diego County. I also wish to build on the current body of knowledge on cancer fatalism by identifying strategies to better understand fatalistic views among underserved populations and develop appropriate interventions.

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Chapter 1

Introduction

Age-related health disparities in breast cancer screening are a public health concern. From 2002 to 2006, the median age for newly diagnosed cases of breast cancer was 61 years and the median age for breast cancer mortality was 68 years of age (Surveillance Epidemiology and End Results [SEER], 2009). The U. S. Preventive Services Task Force (USPSTF, 2009) concluded that the greatest benefit for mortality decrease associated with early breast cancer detection by mammography screening occurs among women 60 to 69 years of age. Findings from the 2005 National Health Interview Survey of women over 65 years of age ($N = 4,683$), indicated that mammography screening is poorly utilized among older women (Leveille, Marcantonio, & Schonberg, 2008). Older women of lower socioeconomic status are at even greater risk for not receiving mammography screening (Williams, Lindquist, Sudore, Covinsky, & Walter, 2008).

The most common risk factor for developing breast cancer is increased age (American Cancer Society [ACS], 2009); hence, breast cancer disproportionately affects

older women. For women over 60 years of age, the probability of developing breast cancer over the next ten years is 1 in 29 women compared to only 1 in 69 women at 40 years of age (ACS, 2009). In the United States, one woman in eight who lives to 85 years of age will develop breast cancer during her lifetime (Albrand & Terret, 2008).

Mammography is the best available screening tool for breast cancer detection (Susan G. Komen Foundation, 2008), and early disease stage at the time of diagnosis is an important predictor of survival. The survival rate is almost 98% for women diagnosed with the earliest stage of breast cancer but only 26% for women diagnosed with more advanced breast cancer (ACS, 2005).

Older women have the highest breast cancer risk, yet they are less likely than younger women to participate in mammography screening. The Centers for Medicare and Medicaid Services (CMS, 2006) reported that only about half of older women who are eligible for mammograms through Medicare obtain a mammogram every two years. This suggests that cost alone is not the primary barrier to mammography participation among older women.

Due to limited epidemiologic studies addressing breast cancer screening in older women, this group comprises one of the most underserved populations, contributing to age-related breast cancer screening disparities. The increase in the elderly population in the United States is likely to increase the incidence of breast cancer as well. Public health interventions to support older women's participation in mammography screening are sorely needed to prevent a consequent increase in breast cancer mortality in this population.

Background and Significance

Numerous randomized trials, as well as population-based screening evaluations, have shown that routine mammography screening reduces the risk of dying from breast cancer (ACS, 2009). In women without symptoms, mammography will detect 80% to 90% of breast cancers. Mammograms have been shown to be more accurate in postmenopausal than premenopausal women. This is due primarily to reduction in breast tissue density in older women, which facilitates early detection of changes and more reliable diagnosis of Stage I disease (Giuliano, Liu, & Wood, 2004). Early detection of breast cancer by mammography increases survival rates and quality of life by allowing a broader range of treatment options.

Literature review indicates that older women are unequally represented in breast cancer clinical trials compared to younger women. The USPSTF's (2009) most recent recommendations concluded that the current evidence is insufficient to assess the additional benefits or harm of screening mammography in women 75 years or older. Although several organizations have offered recommendations for mammography screening in older women, clearly established guidelines as to when mammography screening should occur in this population are lacking. For example, the American Geriatrics Society's (AGS, 2005) most recent position on breast cancer screening in older women recommended screening mammography every 1 to 2 years to age 85 for a woman in average or better health with a life expectancy of at least 5 years. Screening after age 85 is reserved for women with excellent health and functional status and women who feel strongly that they will benefit from mammography screening, either in peace of mind or

improved quality of life. The American Cancer Society (2010) recommended yearly mammograms starting at age 40 and continuing for as long as a woman is in good health.

Because randomized clinical trials suggest that benefit from screening mammography occurs at least 5 years after screening, misconceptions about life expectancy and mammography benefit based on comorbidities and age alone have resulted in screening disparities in this population. In a study conducted by Galit, Green, and Lital (2007), mammography screening was found to reduce breast cancer mortality in older women, including women over 85 years of age, and early detection in women with severe comorbidities was found to still benefit them by limiting additional morbidity caused by metastases. The Newcastle 85+ cohort study found that functional status, rather than disease and age, was the most significant predictor of mortality among the elderly (Bond et al., 2009). The study included 1,042 persons over age 85, and women (62%) outnumbered men (38%); study participants rated their health status and functional ability as good despite significant levels of disease and impairment.

Results from the Newcastle study indicated that functional status, rather than age alone, must be an important consideration in establishing goals of medical treatment in the elderly (Perls, 2009). Since treatment of early stage breast cancer is less burdensome than that of advanced disease, early breast cancer detection by mammography in older women can improve their quality of life and decrease societal costs of care.

Study findings from Williams et al. (2008) indicated that low socioeconomic status among older women with Medicare was linked to decreased utilization of screening mammography. Davis, Marcantonio, McCarthy, Schonberg, and York (2007) concluded that physician recommendation is the most salient factor for older women

making decisions about obtaining a mammogram. In a study conducted by Giuliano, Liu, and Wood (2004), 26% of older women who had not received a mammogram within 2 years reported that their health care provider did not recommend one. Among older women who had never received a mammogram, 39% believed it was not necessary.

Thus, several studies have concluded that physician recommendation is one of the strongest predictors of mammography participation among older women. There is limited research addressing physician recommendation for mammography screening among older, socioeconomically disadvantaged women. Coleman and O'Sullivan (2001) found that physicians were more likely to recommend mammography in older women who were married, had more than a high school education, had annual incomes greater than \$20,000, and had private insurance. This could be due, in part, to underserved women receiving care in community clinics, where physicians are under staffed and have limited patient visit times compared to private offices.

Breen, Graubard, Meissner, Taubman, and Vernon (2007) found that older foreign-born women with less than a high school education were more likely than other women to report that they did not know they needed a mammogram, suggesting that they had either not received or not understood a provider's recommendation. It is unclear whether health care providers are not recommending mammography screening in older patients or women do not remember receiving or understand a recommendation if made. It is evident, however, that adequate communication between older women and their providers about the importance of mammography screening is lacking.

Several studies have shown that awareness and knowledge about breast cancer, cultural beliefs and traditions, family support, language, and anxiety about cancer

influence breast cancer screening participation among older women. Interventions to improve breast health awareness among older women may increase their participation in mammography screening. Because recommendations for mammography screening by health care providers caring for older women have been shown to be a strong predictor of screening participation, health care providers need to emphasize mammography screening among their older patients.

Psychosocial and cultural beliefs about breast cancer screening have also been identified as important determinants of older women's participation in mammography screening. Cancer fatalism, or the belief that cancer is inevitable and that mammography screening is, therefore, not beneficial, is one such cultural belief. Review of the literature suggests that cancer fatalism is most frequently reported among medically underserved persons and those with limited knowledge of cancer (Finnie & Powe, 2003). Several studies have suggested that women who believe that developing breast cancer is a result of fate are less likely to participate in mammography screening because they do not perceive any benefit to screening.

Cancer fatalism has been suggested as an independent predictor of participation in cancer screening not only in elderly women, but in diverse ethnic populations (Baron-Epel, Friedman, & Lernau, 2009). Fatalism is defined as a belief that events are fixed in advance for all time in such a manner that humans are powerless to change them (Fatalism, 2010). Several studies have identified older age, race, and education as predictors of cancer fatalism. Research has suggested that perceptions of cancer fatalism were most evident among women, older persons, persons with lower levels of education, those with decreased income, and racial and ethnic minority groups, and that these

perceptions influenced decisions to participate in cancer screening (Brooks, Hamilton, & Powe, 2006).

A major public health strategy in breast health promotion is to examine perceptions of cancer fatalism and their potential interaction with other barriers to breast cancer screening, including lack of knowledge of cancer. There is a need to identify interventions that modify perceptions of cancer fatalism and promote screening in the older population. Because increased perceptions of cancer fatalism are linked to beliefs that the occurrence of cancer is “the will of a higher power,” spirituality may provide the cultural foundation to effectively address fatalistic perceptions. Other interventions include implementing breast health awareness programs that are culturally and linguistically appropriate for underserved women. Increasing knowledge of breast health may alter fatalistic views, empowering women to engage in healthy lifestyle behaviors.

Problem Statement

Because increased age is identified as the most common risk factor associated with breast cancer (ACS, 2009), older women are disproportionately affected by the disease. Due to increase life expectancy in the older population, as well as aging of the baby boomer generation, a dramatic rise in breast cancer incidence in the elderly is expected (Yarbrough, 2004). Findings from several studies, including a study conducted by Brown and associates (Brown, Garg, Kumarl, Reed, & Wyld, 2004) indicated that older women diagnosed with breast cancer presented with larger tumor size and later stage, were more likely to have metastatic disease at the time of diagnosis, and were less likely to have had a mammogram in the previous two years than younger women. Identifying appropriate interventions to promote breast health awareness and

mammography screening among older women is important in reducing age-related health disparities associated with breast cancer in this underserved population. Older women who are financially or socio-economically disadvantaged are at greater risk of breast cancer mortality (Casella et al., 2010).

Study Purpose

This study is designed to determine the effects of a breast health awareness program on knowledge of and fatalistic attitudes toward breast cancer and breast cancer screening in older women and on their participation in mammography screening. The study goals are to increase breast cancer knowledge, decrease fatalistic attitudes about breast cancer, and increase mammography participation among women over age 65 who participate in senior lunch programs at churches and social service agencies located in underserved areas of San Diego County.

The following research questions will be addressed in the study:

1. Is there a relationship between fatalism and breast cancer knowledge?
2. Is there a relationship between fatalism and mammography participation?
3. Is there a relationship between breast cancer knowledge and mammography participation?
4. Is there a change in breast cancer knowledge as a result of a breast health awareness program?
5. Is there a change in levels of fatalism as a result of a breast health awareness program?

6. Does participation in a breast health awareness program increase mammography screening participation among women 65 years of age and older?

The hypotheses that will be addressed in the study are as follows:

1. There will be a significant negative correlation between fatalism scores and cancer knowledge scores.
2. There will be a significant negative correlation between fatalism scores and mammography participation.
3. There will be a significant positive correlation between breast cancer knowledge scores and mammography participation.
4. Exposure to a breast health awareness intervention will increase older women's knowledge about breast cancer.
5. Increased knowledge of breast cancer in older women will decrease fatalistic attitudes about the disease.
6. Exposure to a breast health awareness intervention will increase older women's participation in mammography screening.

The potential impact of the breast health awareness program on breast cancer will lie in earlier diagnosis of disease in older women through improved screening participation. Earlier diagnosis will permit earlier treatment at less personal and societal cost and result in long-term reduction in breast cancer mortality among older women in San Diego County.

Conceptual Framework

Beliefs and attitudes affect cancer screening behaviors. The conceptual framework chosen for this study is the Health Belief Model (HBM). This model, which emerged in the late 1950's, was used to explain why people did not use preventive health services and, eventually, to understand why people use or fail to use health services in general (Ahmad, Austin, McNally, & Stewart, 2002). The model has been applied in several research studies to guide the development of health interventions to change behavior. During the past decade, the HBM has been tested with older African American women and used to explain and predict breast cancer screening behaviors (D'Agostino, Farmer, Jackson, & Reddick, 2007).

The HBM has six fundamental constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy. The HBM postulates that people will take action to prevent, to screen for, or to control conditions of ill health if they regard themselves as susceptible to the condition, if they believe it could have potentially serious consequences, if they believe that a course of action available to them would be beneficial in reducing either their susceptibility to or the severity of the condition, and if they believe that the anticipated barriers to (or costs of) taking the action are outweighed by its benefits (Champion et al., 2003).

The primary HBM variables to be used in this study are as follows:

Perceived susceptibility and severity. Many women understand that mammography successfully detects breast cancer, but do not see themselves at risk if they are asymptomatic or have no family history of the disease (Ahmad et al., 2002). Perceptions of “cancer as a death sentence” commonly reported by minority and older

people are an example of the perceived severity of the disease. A combination of perceived susceptibility and severity creates a perceived threat of illness.

Perceived benefits. The model concepts of perceived benefits and self-efficacy relate to fatalistic attitudes among some women. Many older women and women of ethnic and minority groups perceive cancer screening as not beneficial based on beliefs that they will either develop cancer or not and that the outcome is beyond their control. This attitude stems from a fatalistic belief that there is little one can do to alter fate or prevent cancer, leading to a sense of powerlessness, which may account for some of the anxiety associated with cancer (Ahmad et al., 2002).

Perceived barriers. Many women perceive a variety of barriers to mammography screening. For example, among Thai American women, family and employment responsibilities were identified as barriers to screening, as was reluctance to display one's breasts. Other logistic barriers to screening included cost, transportation, and language barriers (Clark & Natipagon-Shah, 2008).

Cues to action. Because health care provider recommendation has been shown to increase mammography screening participation, health care provider recommendation is an important cue to action promoting cancer screening. The educational intervention, conducted by a nurse practitioner experienced in motivating underserved, older women to obtain mammography screening, will serve as a cue to action for these women.

These HBM variables will be used to identify older women's perceptions of risk, benefits, and barriers to mammography participation by measuring levels of knowledge and levels of fatalism. It is hypothesized that exposure to a breast health awareness program will increase participants' perceived threat of breast cancer disease, reduce

perceived barriers such as fatalistic views, and increase perceived benefits of screening by increasing knowledge. The conceptual framework for the study is depicted in Figure 1.

Knowledge, fatalism, and perceived threat of disease are potential modifying factors that may change as a result of the educational presentation. All of these factors have been linked with mammography screening (Champion et al., 2003). The model indicates that perceived susceptibility and perceived threat are affected by all three modifiable factors (knowledge, fatalism, and perceived threat). The educational presentation will provide cues to action based on changes in perceived benefit of mammography participation and perceived barriers to behavior change and, hopefully, will increase the likelihood of behavior change. In summary, the educational presentation should directly influence participants' individual perceptions, modifying factors, and cues to action or likelihood that change or action will occur.

Figure 1. Health Belief Model Conceptual Framework

Study Methodology

A quasi-experimental design will be used, in which study participants served as their own controls with respect to changes in knowledge and fatalism related to breast cancer and mammography participation. Sixty women over 65 years of age will be recruited from senior nutrition programs at churches and other social service agencies in underserved areas of San Diego to participate in an educational intervention. The senior lunch programs were selected as an appropriate setting for recruiting participants because women who meet the eligibility criteria would be accessible and because the programs serve low-income elderly individuals from ethnically diverse groups.

Women who consent to participate will be exposed to an educational presentation including a 13 minute video entitled *If I Can Help Somebody: Witnessing to Save Lives*, developed by the Witness Project (Dempsey-Thomas Films, 2004), as well as information about breast cancer and mammography. Following the video presentation, a discussion led by the principal investigator (PI) will address participants' questions and provide information on low-cost or free mammography screening services available in the area.

The effects of the educational presentation on knowledge about breast cancer, fatalistic attitudes, and mammography screening participation will be measured using pre and postintervention testing, including the Revised Powe Fatalism Inventory (rPFI) and a Breast Cancer Knowledge Questionnaire (BRIES). Measurement instruments and study methodology are described in more detail in Chapter Three.

Participants will be followed up at 3 to 6 months. At that time, the PI will revisit the senior lunch programs and obtain a third BRIES questionnaire to measure knowledge,

a second rPFI to measure levels of fatalism, and a mammography questionnaire asking if participants have obtained a mammogram since the educational presentation.

Data Analysis

The three outcome variables to be incorporated in the data analysis include breast cancer knowledge, fatalism, and participation in mammography screening. Descriptive statistics (means, percentages, standard deviations, and standard errors) will be computed for each variable as appropriate.

Summary

In spite of older women's increased risk of developing breast cancer, they are less likely to participate in mammography screening than younger women. Limited existing research addressing breast cancer screening behaviors and barriers among older women in the United States is associated with disparities in early breast cancer detection and prevention among this vulnerable population.

Several studies have shown that knowledge about breast cancer and perceptions of cancer fatalism among older women influence decisions to participate in cancer screening (Brooks, Hamilton, & Powe, 2006). There is a need to identify interventions that modify perceptions of cancer fatalism and promote breast cancer screening in this group. This study will address identified barriers to mammography screening in underserved older women, including breast cancer knowledge and fatalistic beliefs. Study aims are to (a) determine the effects of a breast health awareness program on knowledge of and fatalistic attitudes toward cancer screening and participation in mammography screening among older women and (b) to increase breast cancer screening and decrease

breast cancer-related mortality among older women living in underserved areas of San Diego County.

Chapter 2

Review of the Literature

This study will focus on the effects of a breast health awareness program on knowledge of and fatalistic attitudes toward breast cancer and participation in mammography screening among older women. The literature review will discuss breast cancer morbidity and mortality among older women, screening disparities, and barriers associated with mammography participation decision making among this population. Breast cancer knowledge and cancer fatalism as independent determinants of mammography participation among older women will also be addressed.

Breast Cancer Incidence and Screening Disparities in Older Women

Nearly half of all breast cancer diagnoses and more than half of all breast cancer deaths occur in women over the age of 65 (American Geriatrics Society [AGS], 2005). The single most common risk factor for breast cancer is increased age, creating a major public health concern among the rapidly growing older adult population. In the United States, one woman in eight who lives to 85 years of age will develop breast cancer during her lifetime (Albrand & Terret, 2008).

Although older women represent a large part of the breast cancer population, the literature indicates that they are less likely to obtain mammography screening for early breast cancer detection and less likely to be included in breast cancer clinical trials than younger women. There is no clarity as to why older women have been underrepresented in clinical trials compared to younger women, but this has resulted in a lack of established evidence-based guidelines for regular mammography screening among older women. Internationally agreed upon evidence-based recommendations for the management of breast cancer in elderly women are also lacking because very few women over age 70 have been included in clinical trials, resulting in undertreatment of breast cancer and increased risk of death among this population (Paraskakis & Petrakis, 2010).

The most important predictor of breast cancer survival is stage at diagnosis. The survival rate is almost 98% for women diagnosed at the earliest stage of breast cancer but declines to 26% for women who are diagnosed at more advanced stages (American Cancer Society, 2005). Although older women are more likely than younger women to have hormone dependent tumors (81%), for which hormone treatment can be a successful therapeutic option, with good prognosis if detected early (Paraskakis & Petrakis, 2010), breast cancer screening disparities among older women have been linked to more advanced disease stage at the time of diagnosis and increased breast cancer mortality (Brown et al., 2004).

In addressing issues associated with screening disparities among older women, the literature identifies health care provider recommendation, breast cancer knowledge (including perceived benefits of mammography participation and perceived risk of breast

cancer), and cancer fatalism as potentially modifiable factors relevant to older women's decisions about mammography participation.

Health Care Provider Recommendation

Health care provider recommendation has consistently been acknowledged in numerous studies as the most important factor older women consider when making decisions about obtaining a mammogram. Approximately 80% of women without a mammogram in the previous 2 years reported that the reason they had not obtained a mammogram was because their physicians had not recommended one (Breen et al., 2007; Davis et al., 2007).

Davis et al. (2007) reported that a doctor's recommendation is the most highly ranked factor influencing older women's decisions to obtain a mammogram. In their study, women over 80 years of age who chose not to obtain a mammogram ranked age and then doctor's recommendation as the most important factors influencing their decisions, regardless of their health and functional status. The study stressed the significance of health care providers counseling older women on mammography screening, particularly explaining that health rather than age should be considered when making decisions about obtaining a mammogram.

Lack of clearly identified evidence-based guidelines for mammography screening among older women has made it difficult for health care providers to decide whether or not to recommend mammography screening in this population. This alone makes it even more unlikely that older women will perceive any benefit from participating in screening, since lack of physician recommendation may be misinterpreted as not needing a mammogram (D'Agostino et al., 2007). In a study conducted by Schonberg, Ramanan,

McCarthy, and Marcantonio (2006) to describe physicians' counseling about mammography screening with older women patients, less than half of the physicians interviewed reported that they encouraged screening in women over 80 years of age. In addition, more than half of the physicians reported that they felt uncomfortable discussing stopping screening when addressing risks and benefits of mammography participation. Physicians also noted that the availability of acceptable treatments for elderly women with breast cancer influenced their screening recommendations and suggested that more available data about the risks and benefits of mammography screening among older women will help facilitate discussions about breast cancer screening with older patients.

Improvement in health care provider counseling about mammography screening in older women may lead to improvements in older women's perceptions of the benefit of obtaining a mammogram. This is especially significant in older women who have never obtained a mammogram and perceive less benefit to beginning screening at an older age. In the present study, the nurse practitioner conducting the breast health awareness education program will provide recommendations for screening to motivate participants to obtain mammograms.

Breast Cancer Knowledge

Older women's levels of knowledge of breast cancer risks and symptoms are lower than those of younger women, and they are less likely to seek medical attention promptly for a breast change. A survey study conducted by Linsell, Burgess and Ramirez (2008) to assess knowledge of risks and symptoms of breast cancer in 712 women from 67 to 73 years of age found that the main deficits in knowledge were lack of recognition

of symptoms of breast cancer other than a breast lump and a poor understanding of risk. The authors noted that approximately 75% of survey respondents were not aware that age was a risk factor for breast cancer. This finding was noted even among the most educated group of women, who appeared more likely to believe that older age decreases the likelihood of developing breast cancer. These findings are in line with other research findings, including those of Webster and Austoker (2006), who identified a significantly poorer level of cancer awareness among older age groups. Another large national survey by Beral, Moser, and Patrick (2007) found that only 1% of women were aware that age alone is a risk factor for breast cancer.

Health disparities associated with breast cancer among older women, including advanced disease at time of diagnosis and poor survival rates, may be reduced through interventions appropriately targeted to increase breast cancer and breast health awareness among this vulnerable population. Intervention studies have been shown to be effective in improving both knowledge of breast cancer disease and mammography participation.

An intervention developed by Burgess et al. (2009) to improve breast cancer awareness among older women was found to improve breast cancer knowledge among participants at 1 month postintervention. Knowledge improvements were sustained when measured again at 6 months. Because a breast-related symptom in an older woman is more likely to be breast cancer than in a younger woman, increased breast health awareness and breast cancer knowledge among older women may increase the likelihood that they will seek medical attention promptly and decrease breast cancer mortality in this age group. Older women with limited breast health knowledge are not only less likely to participate in mammography screening, but also less likely to seek medical attention

promptly if a change occurs in their breasts (Burgess et al., 2009). Available data indicate a delay of 3 months or more from the time a woman finds an abnormal lump in her breast until she seeks medical attention. This delay increases breast cancer mortality significantly (Gullatte, Brawley, Kinney, Powe, & Mooney, 2010).

An intervention study was conducted in which a control group received an educational booklet designed to promote breast cancer awareness, and an experimental group received the booklet plus a 10 minute one-to-one interview with a health care provider who reviewed the booklet with the participant as part of the interview. Although results from both groups indicated an increase in knowledge, the group with the health care provider interview scored almost two times higher on the postintervention knowledge assessment compared to the group who received the booklet alone (Burgess et al., 2009). These findings reinforce the importance of health care provider counseling with older women.

Champion et al. (2003) examined the effects of physician recommendations and in-person or telephone counseling breast health awareness interventions on mammography screening among older women. The study found a higher participation in mammography screening among the group that received a physician recommendation in addition to the counseling intervention. Both personal and telephone counseling increased screening participation at 2, 4, and 6 months postintervention. The groups that received a physician recommendation letter in addition to counseling, however, had a 70% increase in participation compared to only 48% for those women who received only questionnaires about mammography screening. Although exposure to the breast health awareness intervention increased mammography participation among older women,

reinforcement of the intervention through a health care provider's recommendation to obtain a mammogram had the most influence on participants' perceived benefits of adhering to yearly mammograms. A valuable strength of this study is that the results were based on medical record findings versus self-report, a limitation noted in many studies, increasing the likelihood that reported mammogram adherence rates were accurate.

Cancer Fatalism

Individual and cultural health beliefs have been known to influence individuals' decisions about seeking health care. Fatalism is one of those beliefs that determine participation in cancer screening, particularly among women, older persons, persons with lower levels of education, persons with decreased incomes, and ethnic minority groups (Brooks et al., 2006). Cancer fatalism, the belief that death is inevitable when cancer is present, has been identified as a barrier to participation in breast cancer screening among older women (Finnie & Powe, 2003). The literature review indicated that perceptions of cancer fatalism were initially identified in qualitative research studies, through focus groups and interviews, as barriers to cancer screening. Until the last decade, however, research designed to measure cancer fatalism as an independent variable in cancer screening decisions was limited.

In 1980, EVVAX, Inc., an African-American-owned evaluation group, conducted the first study sponsored by the American Cancer Society to evaluate perceptions of "cancer as a death sentence" among 750 African American study participants (ACS, 1981). The study addressed many of the obvious disparities in cancer screening and knowledge and preventive health behaviors between African Americans and Caucasians. Study findings indicated that African Americans underestimated the prevalence of

cancer, were pessimistic about its cure, and were less knowledgeable about cancer compared to Caucasians.

In the late 1980s, Freeman's Poverty-Cancer spiral was introduced, in which cancer fatalism was viewed as an interrelationship between race, poverty, and cancer (Freeman, 1989). In 1995, Powe (1995) conducted one of the first theory-based studies utilizing her Powe Fatalism Model to evaluate perceptions of cancer fatalism among elderly African American women. The Powe Fatalism Inventory (PFI), one of the first tools developed to measure levels of fatalism, was developed by the researcher, Barbara Powe (1995) and was used in the study. The results of this study indicated that fatalism was a significant predictor of colorectal cancer screening among elderly African American women. Despite the fact that participants in this study received free transportation to the screening site, received a free educational program on cancer screening, and colorectal cancer screening was provided without cost, elderly African American women did not participate in screening. When demographic factors, such as age, education, and income, were statistically controlled, fatalism was the only significant predictor of colorectal cancer screening participation (Powe, 1995).

Mayo, Parker, & Ureda (2001) examined the relationship between selected demographic factors (race, age, education, resource factors) and fatalism and participation in mammography screening among rural elderly women. A revised version of the PFI, including items specific to breast cancer, was pilot tested and utilized in this study. The study sample consisted of 220 women, with the majority of participants over 70 years of age, of African-American descent, and with less than an 8th grade education. The study supported fatalism as a significant correlate of mammography participation

among elderly women. Study results demonstrated that demographic predictors of fatalism were age, race, and education. Women over 70 years of age, African American women, and women with less than 8th grade education had the highest fatalism scores.

In summary, the literature review identified age-related breast cancer disease disparities among older women. Older women are disproportionately affected by breast cancer; they have the highest level of risk factors and the highest breast cancer mortality rates (ACS, 2009; SEER, 2009). Older women are also less likely than younger women to participate in mammography screening, are less knowledgeable about breast health and their risks for developing breast cancer, and are more likely to have fatalistic perceptions about cancer (Brooks et al., 2006; Burgess et al., 2009).

There is limited research addressing barriers to older women's decision-making regarding mammography participation and their perceptions (including psychosocial and cultural beliefs) about mammography screening. Interventional studies have implied that an increase in breast cancer knowledge may increase mammography participation among older women (Burgess et al., 2009) by reducing cancer-related fatalism, but the consistency of this link has not been demonstrated. This study is intended to address this lack of information. It is designed to determine the effects of a breast health awareness program on knowledge of and fatalistic attitudes toward breast cancer and breast cancer screening in older women and on older women's participation in mammography screening.

Chapter 3

Methodology

This chapter will describe the research design, population, and setting for the study. The methods and procedures for the study intervention and data collection and analysis procedures will also be addressed. The study addresses the following research hypotheses:

1. There will be a significant negative correlation between fatalism scores and cancer knowledge scores.
2. There will be a significant negative correlation between fatalism scores and mammography participation.
3. There will be a significant positive correlation between breast cancer knowledge scores and mammography participation.
4. Exposure to a breast health awareness intervention will increase older women's knowledge about breast cancer.
5. Exposure to a breast health awareness intervention will decrease older women's fatalistic attitudes about the disease.

6. Exposure to a breast health awareness intervention will increase older women's participation in mammography screening.

Design

A quasi-experimental design was chosen for this interventional study because the study examines the effects of the intervention on mammography participation in older women through changes in the relationships among variables of cancer knowledge, cancer fatalism, and mammography participation. The educational cancer awareness presentation is the intervention being studied, and participants will serve as their own controls in measures of knowledge, fatalism, and mammography participation at three different points in time (pre and immediately after intervention and at 3 to 6 months follow-up). Voluntary selection of the sample population may potentially create a significant source of bias, impeding the possibility of obtaining a non-biased randomized sample population (Patten, 2009).

Sample

Study participants will include a non-randomized, volunteer sample of 60 women 65 years of age and older who attend senior nutrition programs at community centers in underserved areas of San Diego County.

Eligibility criteria. Women over 65 years of age, who attend senior lunch programs at community centers located in underserved areas of San Diego County will be invited to participate. Participants will include women with or without personal or family history of breast cancer who are able to speak and read English.

Sample recruitment and protection of human subjects. Power analysis computations based on a 0.05 level of significance, a medium effect size (alpha 0.05),

and an estimated power of .95 (95%) yielded a required sample size of 43. After obtaining permission from the community center senior programs coordinators and IRB approval from the University of San Diego, the primary investigator (PI) will schedule sessions to meet with potential participants during regular lunch program hours. In addition, flyers will be posted in the dining halls one week prior to each scheduled session. The PI will explain the research project and its voluntary nature during scheduled lunch session to groups of older women eligible to participate in the study. Women who express interest in participating will receive written and verbal information about the study's purpose, the voluntary nature of participation, the ability to discontinue participation at any time, confidentiality of the data, and potential risks and benefits of participation prior to agreeing to participate. The PI will review the informed consent form (Appendix A) with prospective participants and obtain two signed copies: one for the participant to take home and another for the PI to keep in a locked file.

Participation in the study may lead to better knowledge of breast cancer, thereby benefitting individual participants. Increased knowledge may result in increased mammography participation leading to the potential for earlier diagnosis and more effective treatment, which can increase participants' longevity and quality of life. In addition to the potential personal benefit to participants, the data generated may lead to more effective strategies to increase mammography participation among older women in general resulting in lower social and financial costs of breast cancer.

Study participation poses minimal risk to subjects. One of the risks may be breach of confidentiality. This will be addressed by maintenance of all study materials in a locked file cabinet accessible only to the investigator and members of her dissertation

committee. Materials will be kept for 5 years, after which they will be destroyed. The study may bring about emotional distress because of the sensitivity of the topic.

Participants will be given contact information for mental health providers in the event that emotional distress occurs. Given the potential general and individual benefits to study participation, anticipated study benefits far outweigh the risks.

Compensation. Participants will receive five dollar gift cards to a local grocery store.

Setting

The study will be conducted at four community centers offering senior lunch programs in underserved areas of San Diego County. The senior lunch programs were selected as an appropriate setting for recruiting participants because women who meet the eligibility criteria would be accessible and because the programs serve low-income elderly. Letters of support for the study will be obtained from each of the lunch program sites (Appendix B). The four different sites will facilitate a larger population sample, representing older women from different underserved areas of San Diego County. The senior lunch programs were selected as an appropriate setting for recruiting participants because women who meet the eligibility criteria would be accessible and because the programs serve low-income elderly individuals from ethnically diverse groups. In addition, providing the educational intervention in the context of a regularly scheduled event (lunch programs) will facilitate participation.

Two sites serve lunch once a day Monday through Friday; 2 sessions will be scheduled at each of these sites. One site delivers meals primarily to homebound seniors and only one session will be scheduled at this facility. The fourth site serves lunch at 3

different times daily Monday through Friday and once daily on Saturday and Sunday.

Four sessions will be scheduled at this facility to accommodate seniors interested in participating. A total of 9 sessions will be conducted for the study.

Data Collection

Study data will be collected from participants using a battery of instruments. Data will be collected prior to the educational presentation, immediately afterwards, and again at 3 to 6 months.

Instruments. Data will be collected using four tools. Participants will complete a demographic questionnaire, the Breast Cancer Knowledge Questionnaire (BRIES), the revised Powe Fatalism Inventory (rPFI), and a postintervention mammography participation questionnaire developed by the PI.

Demographic data questionnaire. A demographic questionnaire (Appendix C) will be used to obtain information regarding participants' age, income, medical insurance coverage, education level, and personal or family history of cancer. The last question on the demographic form elicits information about the subject's last mammogram.

Breast Cancer Knowledge Questionnaire. The Breast Cancer Knowledge Questionnaire, consisting of 15 questions (Appendix D), was derived from the Breast Health Intervention Evaluation Study (BRIES). BRIES was a federally funded intervention study conducted at Morehouse School of Medicine in Atlanta, Georgia to evaluate the effectiveness of three different approaches (a fear approach, a positive approach, and a neutral, cognitive approach) to breast health messages among African-American women living in three rural communities in Georgia. The questionnaire was reviewed by experienced survey and community-based research faculty members at the

Morehouse School of Medicine (MSM) to establish validity. The questionnaire was also reviewed by the MSM IRB and was pre-tested to determine suitability with the target population of the BRIE study (Blumenthal, 2001). The test was used most recently with African American adult daughters of mothers with breast cancer to measure breast health and breast cancer knowledge (Callahan, 2008).

The questions focus on breast health knowledge, including awareness of breast cancer warning signs, and attitudes toward breast cancer. The questionnaire is divided into 3 sections. The first section addresses awareness of breast cancer warning signs. The question “What do you think are the warning signs of breast cancer?” is followed by a list of 10 possible responses, 8 of which are correct and 2 incorrect. Participants are asked to mark each correct item and are given one point for each correct answer for a total of 10 points (8 points for identifying the 8 correct warning signs, and 2 points for not marking the 2 incorrect responses). Higher scores indicate higher levels of knowledge. The second section addresses knowledge of breast cancer and breast cancer screening and includes 5 true/false questions. Each correct answer is given a point for a maximum of 5 possible points; higher scores indicate higher levels of knowledge. Because the questionnaire has not been used in an exploratory analysis, Cronbach’s alphas will be calculated for both sections. The third section measures attitudes about breast cancer and includes Likert-type scale questions. For this section, descriptive analysis will be conducted and responses to each question will be analyzed item by item in terms of frequencies and percents, consistent with past use of the questionnaire (Blumenthal, 2001; Callahan, 2008).

Revised Powe Fatalism Inventory (rPFI). Fatalism, in this study, is defined as the belief that breast cancer is inevitable, and regardless of what is done, leads to death. Fatalism will be measured using the rPFI developed by Mayo, Parker, and Ureda (2001). The rPFI was derived from the original Powe Fatalism Inventory (PFI), a 15-item tool developed by Finnie & Powe (2003) that has been used extensively in studies of breast and other cancers to measure levels of fatalism. The authors of the rPFI (Mayo, Parker, & Ureda, 2001; see Appendix E) revised the original PFI to include 11 items specific to breast cancer and developed the tool through a multi-stage process of qualitative interviews, factor analysis, and multiple revisions. The authors selected the items on the rPFI based on the defining beliefs demonstrated by individuals with strong beliefs in cancer fatalism, which include fear, predetermination, pessimism, and inevitability (including ideas of “God’s will”). The rPFI scales measure the defining characteristics of fatalism related to breast cancer (items 1-3), breast cancer screening (item 4), and the course of cancer and death (items 5-11). There is one item specific to the belief that breast cancer is God’s will.

Response options for each question are yes (scored as one point), or no (scored as zero points). The maximum score is 11 points and higher scores indicate stronger beliefs in cancer fatalism. The rPFI was pilot tested by the authors on a group of 60 elderly women to establish its reliability and validity. The rPFI was found to have a Cronbach’s alpha of 0.89 during pilot testing, which is considered “very good” reliability according to De Vellis (1991). Factor analysis, using principal component analysis, resulted in all items in the pilot scale loading on only one factor with factor loadings of 0.40 or greater

(Mayo et al., 2001). In previous research with the original PFI, Powe (1995) reported a Cronbach's alpha of 0.87.

Mammography participation questionnaire. The postintervention mammography participation questionnaire consists of 2 questions (see Appendix F). The first question is a yes/no type question derived from the BRIE study questionnaire and asks if the participant has obtained a mammogram since the date when the participant attended the educational presentation. If no, participants are asked to indicate reasons why they might not have obtained a mammogram. The first four reasons were derived from the BRIE study as the most common reasons why women do not obtain mammograms. These include: 'I don't believe that mammograms increase my chances of survival', 'I don't believe that I am at risk for breast cancer' 'I am afraid', 'I cannot afford a mammogram'. The last potential reason, 'I don't have transportation,' was added by the PI. The second question is also a yes/no type of question that asks if participants that have not obtained a mammogram since attending the educational presentation intend to do so.

Data collection procedures. Women who consent to participate in the study will be asked to fill out the demographic questionnaire, the Breast Cancer Knowledge Questionnaire, and the revised Powe Fatalism Inventory. Upon completing the questionnaires, participants will be exposed to a group educational presentation, which includes a 13 minute video, "If I Can Help Somebody: Witnessing to Save Lives," developed by the Witness Project,

The Witness Project was initiated in 1990 at the University of Arkansas to increase breast cancer awareness and knowledge about screening and early cancer

detection in the African American population. The program is based, in part, on the African American cultural and spiritual practice of “witnessing,” the sharing of personal stories of struggle, faith, and empowerment (Thompson et al., 2009). The witness project recruits breast cancer survivors, who serve as witness role models, to share their own experience of cancer diagnosis and treatment. The video consists of images of witness role models sharing their own experience of cancer diagnosis, and also stresses the significance of implementing open communication about breast cancer in the community in order to promote early detection. The theoretical framework used to create the Witness Project included a combination of the PRECEDE model, the 4MAT8 system, the Health Belief Model, and Locus of Control. The PRECEDE (predisposing, reinforcing, and enabling causes in educational diagnosis and evaluation) model suggests that health education programs are most effective when they address factors that may predispose, reinforce, or enable a behavior.

In the pilot phase of the Witness Project, the investigators noted that knowledge and awareness needed to be heightened and social norms did not predispose women to participate in cancer screening. The church was viewed as an appropriate setting to reinforce the desired behaviors because at church women can encourage each other to continue their new behaviors (Hurd, Keloney, Maxwell, & Shoate-Gibson, 2004). The same may also be true of relationships developed within senior lunch programs.

The video presentation will be followed by a 30 minute discussion led by the primary investigator (see Appendix G), a community health nurse practitioner with experience working with underserved populations and with motivating women to participate in breast cancer screening. The discussion will address information about

breast cancer (including risks, signs, and symptoms of breast cancer) and mammography screening, as well as participants' questions and information on low-cost or free mammography screening services available in the area.

Immediately following the presentation, participants will be asked to complete the postintervention BRIES questionnaire and reminded that the PI will call them again in 3 to 6 months for a follow up session. The PI will revisit the senior lunch programs at 3 to 6 months and obtain a third BRIES questionnaire, a second rPFI questionnaire, and the mammography participation questionnaire (see Appendix F).

Figure 2. Pre/Postintervention data collection

Data collection and Analysis.

Following the usual lunch at the senior center, participants will complete the three questionnaires, which takes approximately 60 minutes. Completed questionnaires will be reviewed, scored, and entered into a computer database using assigned code numbers.

Quantitative data will be analyzed using SPSS software. Data analysis for outcome variables will include: breast cancer knowledge, fatalism, and participation in

mammography screening. Descriptive statistics will consist of measures of central tendency (e.g., mean, standard deviation, minimum, maximum, frequency distributions) relating to the demographic characteristics of the sample population and study variables. A test will be deemed statistically significant if the probability of error was 5% or less ($\alpha=0.05$). Chi-square analysis will be used to examine relationships between categorized demographic variables (i.e., age, race, income, education) and outcome measures. The paired T-test will be used to examine measures of change in knowledge based on participants pretest and posttest scores from sections 1 and 2 of the BRIES questionnaire. The Wilcoxon matched pairs signed rank test (analogous to the parametric paired t test) will be used to examine measures of change in fatalism levels pre and post intervention. The test was selected because it is designed to be used when subjects serve as their own controls and/ or the outcome variables are measured at different time points. Homogeneity of the instrument tools and their items will be determined by Cronbach's alpha. Hypotheses will be tested using Spearman's rank correlation coefficient, which examines relationships among variables measured on an ordinal scale.

The study addressed the following hypotheses:

1. There will be a significant negative correlation between fatalism scores and cancer knowledge scores.
2. There will be a significant negative correlation between fatalism scores and mammography participation.
3. There will be a significant positive correlation between breast cancer knowledge scores and mammography scores.

4. Exposure to a breast health awareness intervention will increase older women's knowledge about breast cancer.
5. Exposure to a breast health awareness intervention will decrease fatalistic attitudes about breast cancer.
6. Exposure to a breast health awareness intervention will increase older women's participation in mammography screening.

Summary

The study will utilize quantitative methods. Four questionnaires will be utilized to measure the outcome variables. Relationships between demographic variables and mammography participation, as well as levels of knowledge and fatalism will also be examined.

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Appendix A

University of San Diego

Institutional Review Board

Research Participant Consent Form

For the research study entitled:

Breast Health and Mammography Screening in Older Women

I. Purpose of the research study

Martha Ibarra is a student in the Hahn School of Nursing at the University of San Diego. You are invited to participate in a research study she is conducting. The purpose of this research study is to explore mammography participation, fatalism, and breast cancer knowledge among older women.

II. What you will be asked to do

If you decide to be in this study, you will be asked to fill out 3 questionnaires that will ask you information about your perceptions and knowledge of breast cancer. A typical question on these questionnaires is, "What do you think are some of the warning signs and symptoms of breast cancer?" You will also be asked general questions about yourself such as age, income, and personal history of breast cancer. After filling out the questionnaires, you will watch a video about breast cancer and participate in a discussion about breast cancer led by Martha, and you will have the opportunity to speak with Martha to answer any questions you might have about the video or discussion.

Your participation in this study will take a total of 60 minutes on two occasions.

Three to six months later, Martha will call you and make an appointment to fill out the questionnaires again at the senior community center.

III. Foreseeable risks or discomforts

Sometimes when people are asked to think about their feelings, they feel sad or anxious. If you would like to talk to someone about your feelings at any time, you can call toll-free, 24 hours a day:

San Diego Mental Health Hotline at 1-800-479-3339.

There may be a risk that you may feel tired or fatigued while filling out the questionnaires. You can stop at any time to rest, decide not to fill out all the forms, or withdraw from the study anytime.

IV. Benefits

While there may be no direct benefit to you from participating in this study, the indirect benefit of participating will be in knowing that you helped researchers better understand how to help older women improve mammography participation. Knowing more about breast cancer may also help you to make an informed decision about whether or not to get a mammogram.

V. Confidentiality

Any information provided and/or identifying records will remain confidential and kept in a locked file and/or password-protected computer file in the researcher's office for a minimum of five years. All data collected from you will be coded with a number or pseudonym (fake name). Your real name will not be used. During the discussion, you will wear a code number. Please use this number and not your real names. Although I am asking everyone to keep this discussion confidential, there is no guarantee that what you say might be repeated by another group member. The results of this research project may be made public and information quoted in professional journals and meetings, but information from this study will only be reported as a group, and not individually.

VI. Compensation

If you participate in the study, Martha will give you a \$5 gift card to a local grocery store personally on that same day. You will receive this compensation even if you decide not to complete the entire questionnaires.

VII. Voluntary Nature of this Research

Participation in this study is entirely voluntary. You do not have to do this, and you can refuse to answer any question or quit at any time. Deciding not to participate or not answering any of the questions will have no effect on any benefits you're entitled to, like your health care, or your employment or grades. You can withdraw from this study at any time without penalty.

VIII. Contact Information

1) Martha Ibarra, MSN, RN, ANP

Email: marthai-10@sandiego.edu

Phone: (619) 964-4049

2) Dr. Mary Jo Clark, PhD, RN

Email: clark@sandiego.edu

Phone: (619) 260-4574

**I give Martha Ibarra permission to call me in 6 months to make an appointment
_____ (initials)**

My telephone number is _____

I have read and understand this form, and consent to the research it describes to me. I have received a copy of this consent form for my records.

Signature of Participant

Date

Name of Participant (Printed)

Signature of Investigator

Date

Appendix B

Letters of Support

January 12, 2010

Institutional Review Board
University of San Diego

Executive Committee

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Dorothy Devesant
Aron De Mander Meyer

President and CEO
Paul Downey

To whom this may concern:

RE: Letter of Support

I have discussed the research project, "Breast Health and Mammography Screening in Older Women", with Martha Ibarra, NP. I understand that Ms. Ibarra is conducting her study as part of her doctoral dissertation in Nursing. She may use the Senior Nutrition Centers at the following three senior nutrition program sites as a recruitment site as approved by your IRB:

1. St Charles Nutrition Program
945 18th Street, San Diego, CA 92154
2. Beech Center
1151 3rd Avenue, San Diego, CA 92101
3. Broadway Center
928 Broadway, San Diego, CA 92101

I understand that Ms. Ibarra is applying for a dissertation grant from the California Breast Cancer Research Program to help support the study, and that if funded; participants will be compensated for participating in the study with \$25 gift card incentives and free lunch. I would appreciate if you would furnish me with a copy of your schedule and as well as a copy of the survey.

Please call me at (619) 235-6572 x329 if you have any questions or need additional information. Thank you.

Sincerely,

Kitty Roberts, Registered Dietitian
Senior VP of Operations

Chairperson
Harold W. Tuck

President and CEO
Rudolph A. Johnson III

January 11, 2010

To: Institutional Review Board, University of San Diego

From: Jeannette V. [redacted] Program Manager
Senior Nutrition Program

Re: Letter of Support

I have discussed the research project, "Breast Health and Mammography Screening in Older Women", with Martha Ibarra, NP. I understand that Ms. Ibarra is conducting this study as part of her doctoral dissertation in Nursing. The Neighborhood House Association Senior Nutrition Center Senior participants will participate. The address: 795 South Boundary Street, San Diego, CA 92113, will be a recruiting site. As approved by your Internal Review Board. I understand that Ms. Ibarra is applying for a dissertation grant from the California Breast Cancer Research Program to help fund the study. If funded, participants will be compensated for participating in the study with \$25 gift card incentives.

Thank you.

Appendix C
Demographic Data Questionnaire

Subject ID #: _____ Date: _____ Site: _____

Please fill in the blank or check the correct response.

1. Please check an age group: 65-69 _____ 70-74 _____ 75-79 _____ 80+ _____

2. Race(check all that apply): African-American _____ Caucasian _____ Hispanic _____
Asian _____ Other-Specify _____

3. What was your household income last year?

- ☐ o Less than \$10,000
- ☐ o \$10,000 -\$14,999
- ☐ o \$15,000 -\$24,999
- ☐ o \$25,000 -\$34,999
- ☐ o \$35,000 -\$49,999
- ☐ o \$50,000 or more
- ☐ o Unknown

4. What is your health care insurance coverage? (check all that apply)

- ☐ o Private insurance
- ☐ o Medicaid
- ☐ o Medicare
- ☐ o None
- ☐ o Other -Specify: _____

5. What level of education have you completed?

- ☐ o Less than high school graduate
- ☐ o High school graduate
- ☐ o Some college or technical school
- ☐ o College graduate
- ☐ o Advanced college degree
- ☐ o Other – Specify: _____

6. Have you ever had breast cancer? Yes _____ No _____

7. Has anyone in your family had breast cancer (mother, sister, daughter)? Yes ____ No ____

8. When was your last mammogram?

- ☐ o Less than 12 months ago
- ☐ o 12 to 24 months ago
- ☐ o More than 24 months ago

Appendix D
Breast Cancer Knowledge Questionnaire
Breast Health Intervention Evaluation (BRIE)

Subject ID#: _____ Survey Date: _____ Site Location: _____

1. What do you think are some of the warning signs or symptoms of breast cancer? (Put an X beside each item you think is CORRECT)

- a. A new lump in the breast _____
- b. A lump that has changed _____
- c. Shortness of breath _____
- d. Pain, soreness, burning in the breast or nipple _____
- e. Nausea _____
- f. Fluid leaking from the nipple _____
- g. Swelling or enlargement of the breast _____
- h. A change in the size or shape of the breast or nipple _____
- i. Changes in the color of the skin on the breast _____
- j. A nipple that is very tender or that suddenly turns inward _____

For the next five questions, circle **T** if you think the statement is True and **F** if you think the statement is False.

- 1. Mammograms are not very effective at detecting breast cancer. T__ F__
- 2. Breast cancer is more difficult to cure if detected early. T__ F__
- 3. Mammograms can cause breast cancer. T__ F__
- 4. Women who do monthly breast self-examinations are more likely to find a lump that could indicate a problem. T__ F__
- 5. Getting older raises a woman's chance of getting breast cancer. T__ F__

GO ON TO THE NEXT PAGE

For the rest of the questions, circle the number that most closely describes your agreement or disagreement with each statement.

	STRONGLY AGREE	MOSTLY AGREE	NEITHER AGREE NOR DISAGREE	MOSTLY DISAGREE	STRONGLY DISAGREE
7. I am responsible for taking care of my own body, including my own breasts.	1	2	3	4	5
8. Mammograms can hurt.	1	2	3	4	5
9. Breast cancer is the will of the Lord.	1	2	3	4	5
10. I would be more likely to get a mammogram if my doctor told me I should.	1	2	3	4	5
11. I would be more likely to get a mammogram if I was encouraged or supported by someone close to me (husband, best friend, sister, etc.)	1	2	3	4	5
12. I think mammograms are worth it.	1	2	3	4	5
13. I don't want to get a mammogram because I am afraid of what it might show.	1	2	3	4	5
14. Getting a mammogram is embarrassing.	1	2	3	4	5
15. I am not afraid of getting a mammogram.	1	2	3	4	5

Appendix E

Revised Powe Fatalism Inventory (rPFI)

DIRECTIONS:

The following questions are concerned with health issues of women your age. Put an X beside YES or NO under each statement to answer each question. Please answer the questions based on what you think.

Remember that there are no right or wrong answers. Do you have any questions before starting this section?

1) I believe if someone gets breast cancer it was meant to be.

☐ YES ☐ NO

2) I believe if someone is meant to get breast cancer they will get it no matter what they do.

☐ YES ☐ NO

3) I believe if someone is meant to have breast cancer they will have breast cancer.

☐ YES ☐ NO

4) I believe if someone was meant to have breast cancer it doesn't matter what the doctor tells them to do, they will get breast cancer anyway.

☐ YES ☐ NO

5) I believe if someone gets breast cancer it is part of God's plan.

☐ YES ☐ NO

6) I believe if someone gets breast cancer it doesn't matter when they find out about it, they will still die.

☐ YES ☐ NO

GO ON TO NEXT PAGE, PLEASE

7) I believe if someone has breast cancer it is already too late to do anything about it.

☐ YES ☐ NO

8) I believe if someone gets breast cancer their time to die is near.

☐ YES ☐ NO

9) I believe if someone gets breast cancer that's the way they were meant to die.

☐ YES ☐ NO

10) I believe if someone gets breast cancer a lot of different treatments won't make a difference.

☐ YES ☐ NO

11) I believe breast cancer kills most people who get it.

☐ YES ☐ NO

Appendix F

Mammography Participation Questionnaire

Subject ID#: _____ Survey Date: _____ Site Location: _____

Have you received a mammogram since you watched the video about breast cancer screening? Yes _____ No _____

If No, please mark all statements that explain why you did not obtain a mammogram

_____ I don't believe that a mammogram increases my chances of survival

_____ I don't believe that I am at risk for breast cancer

_____ I am afraid

_____ I cannot afford it

_____ I don't have transportation

If you did not obtain a mammogram since you watched the video about breast cancer

screening, do you intend to obtain one in the next 6 months? Yes _____ No _____

Appendix G

Postintervention Discussion

- I. What is breast cancer?
 - a. A disease in which cells in the breast become abnormal and grow faster than normal cells forming a lump or a tumor
- II. Breast cancer information
 - a. We don't know what causes breast cancer
 - b. Finding it early is the key to survival - Based on fair evidence, screening mammography in women aged 40 to 70 years decreases breast cancer deaths. The benefit is higher for older women, in part because their breast cancer risk is higher (National Cancer Institute [NCI], 2010)
 - c. All women are at risk
- III. Breast cancer risk factors
 - a. Age- the most important risk factor for breast cancer
 - i. Breast cancer is more common in women over age 60 and is relatively uncommon in women under age 40 (NCI, 2010)
 - b. Menstrual periods before age 12 or menopause after age 55
 - c. Having a personal history of breast cancer
 - d. Although most breast changes are not cancer, certain benign breast diseases associated with increased risk of breast cancer include:
 - i. Atypical hyperplasia(increased number of abnormal cells)
 - ii. Lobular Carcinoma in Situ (abnormal cells in the lobules of the breasts)(better tell them which ones or you will confuse or scare them)
 - e. Having close family relatives (mother, sister, father, or daughter) who have had breast cancer
 - f. Having been treated with radiation therapy to the breast or chest
 - g. Long term use (more than five years) of hormone replacement therapy
 - h. Alcohol use
- IV. Breast cancer signs and symptoms
 - a. A new lump in the breast, usually single, firm, and most often painless
 - b. A lump that has changed
 - c. A change in the size or shape of the breast or nipple
 - d. Swelling or enlargement of the breast
 - e. Changes in the color of the skin on the breast
 - f. Pain, soreness, or burning in the breast or nipple
 - g. A nipple that is very tender or suddenly turns inward
 - h. Blood or any other type of fluid leaking from the nipple
- V. Not all lumps are cancer
 - a. 4 out of 5 lumps are not cancer
 - b. The only way to find out is to see a healthcare provider
- VI. Steps to finding out
 - a. Yearly clinical breast exams by a healthcare provider
 - b. Mammograms
 - i. Starting at age 50 and every two years after
 - ii. If you have any symptoms or changes in your breast, or personal or family history of breast cancer, your healthcare provider may

recommend that you have a mammogram before age 50 or more often than usual

- VII. **Mammography facts**
 - a. An x ray picture of the breast
 - b. Allow doctors to look for early signs of cancer, sometimes up to three years before a lump can be felt
 - c. Can miss up to 20% of cancers, more often among younger women
 - d. Easier to read in older women due to less breast density
- VIII. **Mammography**
 - a. Before getting a mammogram (the day of the appointment)
 - i. No deodorant, bath powder, perfume, or lotions
 - ii. Wear a 2 piece outfit
 - b. Special x ray machine
 - i. Each breast will be placed on an x ray platform and you will feel some squeezing or pinching
 - ii. The plates will hold your breasts still while the x ray is being taken
 - c. Always get the results of your mammogram from your doctor
- IX. **What happens if my mammogram is abnormal?**
 - a. Does not mean you have cancer
 - b. You will need some additional x rays or other tests before your doctor can be sure if you have cancer
 - c. Follow your doctor's recommendations
- X. **Why find breast cancer early?**
 - a. More treatment options
 - b. Treatment is more effective
 - c. Increases chances of survival
- XI. **Where can I find a free or low cost mammogram?**
 - a. Medicare covers screening mammograms once every 12 months for women 40 and older. Starting January 1, 2011, you pay nothing for the test if the doctor accepts assignment.
 - b. 1-800-CDC-INFO
 - c. Family Health Centers of San Diego
1809 National Ave, San Diego, CA 92113

(619) 515-2300 Cancer Detection Program
- XII. **Participants will be asked to fill out the Breast Cancer Knowledge Questionnaire (Appendix D) again. Thank participants politely, and remind them that PI will call them in 3 to 6 months to fill out questionnaires again.**

Appendix H

Permission to Use Revised Powe Fatalism Inventory

Martha Ibarra <marthai-10@san-diego.edu>

PFI

6 messages

Martha Ibarra <marthai-10@san-diego.edu>
 To: rmayo@clermson.edu

Thu, Jan 7, 2010 at 3:56 PM

Dear Dr. Mayo,

I am a Doctoral student at the University of San Diego. I am currently working on my proposal and I am interested in looking at mammography screening and cancer fatalism among women over age 65 who attend senior lunch programs in underserved churches throughout San Diego county. In my research proposal, I would like to utilize your revised 11 item Powe Fatalism Inventory tool to assess fatalism in the study population. I would like to obtain permission to use the your revised version of the PFI tool, and information on how to access it. Thank you for your consideration.

Sincerely,

Martha Ibarra

Rachel Mayo <RMAYO@clermson.edu>
 To: Martha Ibarra <marthai-10@san-diego.edu>

Fri, Jan 8, 2010 at 8:36 AM

Martha-

You have my permission to use the revised PFI tool. Please see attached. Best of luck,

-R. Mayo

From: Martha Ibarra [mailto:marthai-10@san-diego.edu]
Sent: Thursday, January 07, 2010 6:57 PM
To: Rachel Mayo
Subject: PFI

fatalismINSTRUFi.doc
 25K

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MANUSCRIPTS

California Breast Cancer Research Program Grant Proposal
Breast Health and Mammography Screening in Older Women

Principal Investigator: Ibarra, Martha;

SCIENTIFIC ABSTRACT

Background and overall topic: Age-related health disparities in breast cancer screening are a public health concern. According to the American Cancer Society (ACS, 2009), increased age is the most common risk factor for developing breast cancer. Although the risk of breast cancer increases with age, older women are less likely than younger women to be routinely screened. Statistics show that even though Medicare pays for yearly mammograms, only about one-half of eligible women receive one every 2 years (Giuliano, Liu, & Wood 2004). Several studies have shown that knowledge about breast cancer and perceptions of cancer fatalism among older women influenced decisions to participate in cancer screening (Brooks, Hamilton, & Powe 2006). Cancer fatalism has been suggested as an independent predictor of participation in cancer screening in older women and minority groups (Baron-Epel, Friedman, & Lerneu, 2009). There is a need to identify interventions that modify perceptions of cancer fatalism and promote screening in the older population.

Hypothesis/questions addressed: The following hypotheses will be addressed in the study: (a) exposure to a breast health awareness intervention will increase older women's knowledge about breast cancer; (b) exposure to a breast health awareness intervention will increase older women's participation in mammography screening; and (c) increased knowledge of breast cancer in older women will decrease fatalistic attitudes toward the disease.

Objectives/aims: The goals of the study are to (a) increase breast cancer knowledge, (b) decrease fatalistic attitudes toward breast cancer, and (c) increase mammography participation among women over age 65 in San Diego County. The specific aims of the study are to (a) determine the effects of a breast health awareness program on knowledge of and fatalistic attitudes toward cancer screening in older women, and (b) determine the effects of a breast health awareness program on older women's participation in mammography screening.

Methods and approaches: The proposed interventional study using a quasi-experimental design will include sixty women over 65 years of age recruited from three senior nutrition programs at churches and senior community centers in underserved areas of San Diego. The intervention will take place at regularly scheduled lunch session at all three sites. The educational presentation will include a 13 minute video followed by a discussion led by the PI, a nurse practitioner experienced in caring for older populations and motivating women to participate in mammography screening. The discussion will address participant questions and information about free or low cost mammography screening in the local area. Study participants will serve as their own controls with respect to changes in knowledge and fatalism related to breast cancer and mammography participation by means of pre- and post-intervention questionnaires, which include a demographic data questionnaire, the BRIE breast cancer knowledge test, and the revised Powe Fatalism Inventory (rPFI) tool. A 6 month post-intervention follow-up visit will be scheduled at the 3 lunch sites. At that time, participants will be asked to complete post-intervention rPFI inventories and breast cancer knowledge tests. Participants will also be asked if they have obtained a mammogram since the presentation. Descriptive statistics (means, percentages, standard deviations, and standard errors) will be computed for each variable as appropriate. Generalized estimating equations (GEE) will be used to look at the relationship of fatalism to breast cancer knowledge over time, and to look at the relationship of knowledge and fatalism to mammography participation.

Impact on breast cancer: The potential impact of the project will lie in earlier diagnosis of breast cancer disease in older women through improved screening participation. Early detection of breast cancer is linked to less metastasis and smaller tumor size at time of diagnosis, which leads to less radical surgery, less disfigurement and disability, better quality of life, and increased survival rates (Giuliano, et al., 2004). Earlier diagnosis will permit earlier treatment at less personal and societal cost and result in long-term reductions in breast cancer mortality among older women in San Diego County.

Advocacy involvement and sensitivity to advocacy concerns: The PI is a nurse practitioner and has 6 years clinical experience working in a community clinic serving vulnerable older people who reside in an underserved area of San Diego County. She is one of the primary care providers for the Breast Cancer Clinic, funded through the California Cancer Detection Program, which provides clinical breast exams and mammograms to underserved women. The project will improve her ability to disseminate study findings to the community through her activities at the community clinic.

Principal Investigator: Ibarra, Martha
 Institution: University of San Diego

LAY ABSTRACT

Grant Title: Breast Health and Mammography Screening in Older Women

Non-technical overview of the research topic and relevance to breast cancer: Women over 65 years of age account for 44% of new breast cancer cases and 59% of breast cancer deaths each year (National Cancer Institute, 2005). According to the American Cancer Society (ACS), increased age is a common risk factor for breast cancer (ACS, 2009). Although older women have the highest breast cancer risk, they are less likely than younger women to participate in mammography screening. Statistics from the most recent Medicare report show that only about one half of eligible older women obtain a mammogram every two years (Centers for Medicare and Medicaid Services [CMS], 2006). In a study conducted by Giuliano, Liu, and Wood (2004) 26% of older women who had not received a mammogram within 2 years reported that their healthcare provider did not recommend one. Among older women who had never received a mammogram, 39% believed it was not necessary. Social, psychological, and cultural barriers to cancer screening among older women, including cancer fatalism or the belief that cancer is inevitable, have been shown to influence older women's perceptions of the benefits of mammography screening. Failure to include older women in breast cancer research studies has resulted in limited knowledge of mammography screening benefits, not only among older women but among health care providers as well. There is a need for further studies addressing barriers and programs to improve cancer screening among older women.

The question(s) or central hypotheses of the research: The hypotheses addressed in the study are: (a) Exposure to a breast health education presentation will increase older women's knowledge about breast cancer, (b) Exposure to a breast health education presentation will increase older women's participation in mammography screening, and (c) Increased knowledge about breast cancer among older women will decrease fatalistic attitudes toward the disease.

The general methodology: Sixty women over 65 years of age will be recruited from senior nutrition programs at churches and senior community centers in underserved areas of San Diego to participate in an educational intervention. Women who agree to take part in the study will participate in an educational presentation which will include a video, followed by a discussion lead by a nurse practitioner experienced in community health and breast cancer screening in older women. The discussion will address participant's questions and provide information on low cost or free mammograms in the area. Participants will fill out pre- and post-intervention questionnaires and tools to assess breast cancer knowledge and fatalistic attitudes toward breast cancer. A six month follow up will be scheduled to evaluate breast cancer knowledge and fatalistic perceptions as well as mammography participation, by repeating the breast cancer knowledge test, the revised Powe Fatalism Inventory, and a questionnaire asking participants if they have obtained a mammogram within the previous 6 months.

Innovative elements of the project: An educational intervention in the context of older women's scheduled routines and in a non-threatening environment where they have a sense of belonging, such as a church or social setting, may increase the likelihood of participation in the intervention, thereby increasing the potential for change related to screening behaviors. In addition, presenting the intervention within an existing social group, a senior lunch program, with established relationships to others, may lead the women to encourage one another to get mammograms.

Advocacy involvement and relevance to the human issues associated with breast cancer: Older women have the highest risk of breast cancer, yet they are often not screened or included in research studies. The Susan G. Komen Advocates in Science proposes to eliminate disparities in early breast cancer detection among underserved women, including older women. The research study addresses age-related disparities in breast cancer screening by targeting barriers to mammography screening in older women, including lack of knowledge about breast cancer and fatalism.

Principal Investigator: Ibarra, Martha

RESEARCH PLAN

Introduction and Hypotheses:

Age-related health disparities in breast cancer screening are a public health concern. From 2002 to 2006, the median age for newly diagnosed cases of breast cancer was 61 years and the median age for breast cancer mortality was 68 years of age (Surveillance Epidemiology and End Results [SEER], 2009). According to the American Cancer Society (ACS, 2009), increased age is the most common risk factor for developing breast cancer. For women over 60 years of age, the probability of developing breast cancer over the next ten years is 1 in 29 women compared to only 1 in 69 women for those 40 years of age (ACS, 2009). Mammography is the best available screening tool for breast cancer detection (Susan G. Komen Foundation, 2008), and early disease stage at time of diagnosis is an important predictor of survival. The survival rate is almost 98% for women diagnosed with the earliest stage of breast cancer but only 28% for women diagnosed with more advanced breast cancer (ACS, 2005).

Although older women have the highest breast cancer risk, they are less likely than younger women to participate in mammography screening. The Centers for Medicare and Medicaid Services (CMS, 2006) reported that only about half of older women who are eligible for yearly mammograms through Medicare obtain a mammogram every two years. This suggests that cost alone is not a primary barrier to mammography participation among older women. In a study conducted by Giuliano, Liu, and Wood (2004) 26% of older women who had not received a mammogram within 2 years reported that their healthcare provider did not recommend one. Among the older women who had never received a mammogram, 39% believed it was not necessary.

There is limited breast cancer research addressing the benefits of mammography screening in older women, as well as psychosocial and cultural beliefs about breast cancer screening, which are important determinants of older women's participation in mammography screening. One of these influencing beliefs is fatalism, or the belief that cancer is inevitable therefore mammography screening is not beneficial.

Due to limited epidemiologic studies addressing breast cancer screening in older women, this population comprises one of the most underserved populations contributing to age-related breast cancer screening disparities. The increase in the elderly population in the United States is likely to increase the incidence of breast cancer as well. Public health interventions to support older women's participation in mammography screening are sorely needed to prevent a consequent increase in breast cancer mortality in this population.

The proposed research project addresses CBCRP's priority issues in detection, prognosis, and treatment of breast cancer to promote mammography screening and early breast cancer detection among older women. The following hypotheses will be addressed in the study:

1. Exposure to a breast health awareness intervention will increase older women's knowledge about breast cancer.
2. Exposure to a breast health awareness intervention will increase older women's participation in mammography screening.
3. Increased knowledge of breast cancer in older women will decrease fatalistic attitudes about the disease.

Specific Aims:

The goals of the proposed study are to:

1. Increase breast cancer knowledge and decrease fatalistic attitudes about breast cancer
2. Increase mammography participation among women over age 65 who participate in senior lunch programs at churches and social services agencies located in underserved areas of San Diego County.

Principal Investigator: Ibarra, Martha

The specific aims of the study are to:

1. Determine the effects of a breast health awareness program on knowledge of and fatalistic attitudes toward breast cancer and breast cancer screening in older women.
2. Determine the effects of a breast health awareness program on older women's participation in mammography screening.

The research questions to be addressed in the study are as follows:

1. Is there a change in breast cancer knowledge over time as a result of a breast health awareness program?
2. Is there a relationship between fatalism and breast cancer knowledge?
3. Is there a relationship between fatalism and mammography participation?
4. Is there a relationship between breast cancer knowledge and mammography participation?

Background and Significance:

Numerous randomized trials, as well as population-based screening evaluations, have shown that routine mammography screening reduces the risk of dying from breast cancer (ACS, 2009). In women without symptoms, mammography will detect 80% to 90% of breast cancers. Mammograms have been shown to be more accurate in postmenopausal than premenopausal women. This is due primarily to loss of breast tissue density in older women, which facilitates early detection of changes, leading to more reliable diagnosis of Stage I disease (Giuliano, Liu, & Wood, 2004). Early detection of breast cancer by mammography increases survival rates and quality of life by allowing a broader range of treatment options.

Findings from several studies, including a study conducted by Brown and associates (Brown, Garg, Ku, arl, Reed, & Wyld, 2004) indicated that older women diagnosed with breast cancer presented with larger tumor size and later stage, were more likely to have metastatic disease at the time of diagnosis, and were less likely to have had a mammogram in the previous two years than younger women. In part, low mammography screening rates in women 65 years of age and older may be due to lack of consensus about screening intervals and the age at which to stop routine screening (Freeman, Goodwin, Mahnken, & Randolph, 2002). In a study to identify barriers to mammography participation in older women, the most common reason reported for not having routine mammograms is lack of health care provider recommendation. Among women who had never had a mammogram, 39% believed it was not necessary (Giuliano et al., 2004).

Despite recent controversy about the age for initiating mammography screening, the American Cancer Society and the National Cancer Institute recommend annual mammography for all women 40 years of age or older, with no upper age limit. Several studies have shown that awareness and knowledge about breast cancer, cultural beliefs and traditions, family support, language, and anxiety about cancer influence breast cancer screening participation among older women. Interventions to improve breast health awareness among older women may increase their participation in mammography screening. Increasing knowledge of breast health may alter fatalistic views, empowering women to engage in healthy lifestyle behaviors. Because recommendations for mammography screening by healthcare providers caring for older women have been shown to be a strong predictor of screening participation, health care providers need to emphasize mammography screening among their older patients.

Cancer fatalism has been suggested as an independent predictor of participation in cancer screening not only in elderly women, but in diverse ethnic populations (Baron-Epel, Friedman, & Lerner, 2009). Fatalism is defined as a belief that events are fixed in advance for all time in such a manner that humans are powerless to change them (Fatalism, n.d.) Several studies have identified older age, race, and education as predictors of cancer fatalism. Research has suggested that perceptions of cancer fatalism were most evident among women, older persons, persons with lower levels of education, those with decreased income, and racial and minority groups; and that these perceptions influenced decisions to participate in cancer screening (Brooks, Hamilton, & Powe 2006). A major public health strategy in breast health promotion is to examine perceptions of cancer fatalism and their potential interaction with other barriers to breast cancer screening, including lack of knowledge of cancer. There is a need to identify interventions that modify perceptions of cancer fatalism and promote screening in the older population. Because increased perceptions of cancer fatalism are linked to

Principal Investigator: Ibarra, Martha

beliefs that the occurrence of cancer is "the will of a higher power", spirituality may provide the cultural foundation to effectively address fatalistic perceptions. Other interventions include implementing breast health awareness programs that are culturally and linguistically appropriate for underserved women.

Beliefs and attitudes affect cancer screening behaviors. The conceptual framework chosen for this study is the Health Belief Model. This model, which emerged in the late 1950's, was used as an exploratory model to assess why people did not use preventive health services and eventually to understand why people use or fail to use health services (Ahmad, Austin, McNally, & Stewart, 2002). The model has been applied in several research studies to guide the development of health interventions to change behavior. During the past decade, the HBM has been tested with older African American women and used to explain and predict breast cancer screening behaviors (D'Agostino, Farmer, Jackson, & Reddick, 2007).

The HBM has six fundamental constructs: perceived susceptibility, perceived seriousness, perceived benefits, perceived barriers, cues to action, and self-efficacy. Concepts of perceived benefits and self-efficacy relate to fatalistic attitudes among some women. Many older women and women of ethnic and minority groups perceive cancer screening as not beneficial based on beliefs that they will either develop cancer or not and that the outcome is beyond their control. This attitude stems from a fatalistic belief that there is little one can do to alter fate or prevent cancer, leading to a sense of powerlessness which may account for some of the anxiety associated with cancer (Ahmad et al., 2002).

Many women understand that mammography successfully detects breast cancer, but do not see themselves at risk if they are asymptomatic or have no family history of the disease (Ahmad et al., 2002). In addition, because healthcare provider recommendation has been shown to increase mammography screening participation, health care provider recommendation is an important cue to action promoting cancer screening. Finally, many women perceive a variety of barriers to mammography screening. For example, among Thai American women, family and employment responsibilities were identified as barriers to screening, as was reluctance to display one's breasts. Other logistic barriers to screening included cost, transportation, and language barriers (Clark & Natipagon-Shah, 2008).

Dr. Mary Jo Clark will serve as a research mentor for the dissertation and has experience conducting breast cancer research with minority women. She also has expertise in using the Health Belief Model as a foundation for programs to promote healthy behaviors. Her guidance will be helpful in assisting the primary investigator to expand her research skills in a community setting. The PI is a novice researcher, who has extensive clinical experience as a nurse practitioner in primary care with older women. The project will improve her research skills and her clinical abilities to motivate screening participation in her clientele.

The potential impact of the project on breast cancer will lie in earlier diagnosis of disease in older women through improved screening participation. Earlier diagnosis will permit earlier treatment at less personal and societal cost and result in long-term reduction in breast cancer mortality among older women in San Diego County.

Preliminary Results:

The principal investigator has not conducted prior research related to breast cancer or mammography screening. The PI has extensive clinical experience as an oncology nurse working with women affected by breast cancer, as well as advocating to ensure optimal fulfillment of their physical and psychosocial needs. In particular, the PI has experience working with older Spanish-speaking minority women who require extensive breast health education that is culturally relevant. In her current nurse practitioner position, the PI manages her own case load of underserved older women functioning as their primary care provider where she is able to provide appropriate breast health education and motivate older women to participate in mammography screening. In addition, the PI participates in monthly health care provider clinic meetings with the clinic directors to address patient care needs and program planning for several grant-funded programs at the community clinic. The PI's feedback regarding her clientele's needs, allows her an opportunity to advocate and participate in grant-funded program enhancement to improve health care delivered to the underserved at her clinic. The proposed research project will enhance the PI's ability to disseminate the study findings to program

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and clinic directors during the monthly meetings, enhancing effective program planning for improving mammography screening in older women who seek medical care throughout the community clinic's organization. Currently, there are 13 clinics within the organization located in underserved areas of San Diego County where free mammography screening is funded through the California's Cancer Detection Program.

Research Design and Methods:

A quasi-experimental design will be used in which sixty women over 65 years of age will be recruited from senior nutrition programs at churches and other social service agencies in underserved areas of San Diego to participate in an educational intervention. Study participants will serve as their own controls with respect to changes in knowledge and fatalism related to breast cancer and mammography participation. Pre- and post-intervention tests and inventories will be used to assess knowledge, fatalistic attitudes, and mammography participation.

Power computations were calculated by a statistician for a one group, repeated measures design with 3 time points. The computations were based on a 0.05 level of significance with a medium effect size (alpha 0.05) and an estimated power of .95 (95%) to yield a total sample size of 43. To account for attrition over time, the sample size for the proposed study was inflated to 60. Measurement instruments and study methodology are described in more detail below.

Sample and Subject Recruitment: The target population for the intervention study consists of sixty women 65 years of age and older who attend senior nutrition programs at churches and senior community centers in low income areas of San Diego County. The senior lunch programs were selected as an appropriate setting for recruiting participants because women who meet the eligibility criteria would be accessible and because the programs serve low-income elderly individuals from ethnically diverse groups. In addition, providing the educational intervention at a regular, scheduled event for the women facilitates participation. A sign in sheet will be kept to keep count of the number of participants.

After approval by the University of San Diego's IRB, the research project and its voluntary nature will be explained to groups of women who currently participate in the senior nutrition programs. Those who wish to participate will sign two copies of the consent form. Once copy will be given to the participant and a second copy will be kept by the investigator in a locked file.

Intervention: Women who consent to study participation will be exposed to an educational presentation which will include a 13 minute video "If I can help somebody: Witnessing to save lives" taken from the Witness Project, as well as information about free or low cost mammography screening in the local area.

The Witness Project was initiated in 1990 at the University of Arkansas to increase breast cancer awareness and knowledge about screening and early cancer detection in the African American population. The theoretical framework used to create the Witness Project includes a combination of the PRECEDE model, the 4MAT8 system, the Health Belief Model, and Locus of Control. The PRECEDE (predisposing, reinforcing, and enabling causes in educational diagnosis and evaluation) theory suggests health education programs are most effective when they address factors that may predispose, reinforce, or enable a behavior. In the pilot phase of the Witness Project, the investigators noted that knowledge and awareness needed to be heightened and social norms don't predispose women to participate in cancer screening. The church is an appropriate setting to reinforce the desired behaviors because at church women can encourage each other to continue their new behaviors (Hurd, Keloney, Shoate-Gibson, & Maxwell 2004). The same may also be true of relationships developed within senior lunch programs.

The Health Belief Model has been one of the most influential theories utilized to understand health related behavior. The HBM consists of 3 distinct phases that lead to an action related to health: (a) individual perceptions, (b) modifying factors, and (c) likelihood of action. The likelihood a person will take a preventive

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health action depends on perceived benefits of the action, minus the perceived barriers or costs of the action (Hurd et al., 2004). In the video, breast cancer survivors share their stories with other women to convey that they, too, are susceptible to a serious illness such as cancer, that early detection through screening can enhance their ability to survive and undergo less severe medical treatment, and that low cost or free mammogram screening is available (Hurd et al., 2004). The ability to identify themselves with other minority, underserved women in the video presentation, has been shown to motivate women who have participated in the Witness Project to make positive behavior changes and increase mammography screening.

The video presentation will be followed by a discussion lead by the PI, a nurse practitioner with experience in motivating women to participate in breast cancer screening. The discussion will address participant questions and provide information on low cost or free mammography screening services available in the area.

Measurement:

Knowledge and Outcomes: The effects of the educational presentation on knowledge about breast cancer, fatalistic perceptions, and mammography screening will be measured using pre- and post-intervention testing. Prior to starting the educational presentation, participants will be asked to complete pre-intervention measures including: (a) a demographic questionnaire, (b) the Revised Powe Fatalism Inventory [rPFI], and (c) the Breast Cancer Knowledge Questionnaire. The demographic questionnaire (Appendix A-1) addresses age, income, medical insurance coverage, personal or family history of cancer. The last question on the demographic form elicits information about the subject's last mammogram. The rPFI (Appendix A-2) has been pilot tested by the authors of the tool Mayo, Parker, & Ureda (2001) among rural elderly women to establish its reliability and validity. The rPFI was found to have a Chronbach's alpha of 0.89. The original PFI is a 15 item tool developed by Powe & Finnie (2003) and has been used extensively in studies of breast and other cancers to measure levels of fatalism. The rPFI includes 11 questions specific to breast cancer that are based on the defining beliefs demonstrated by individuals with strong beliefs in cancer fatalism: fear, predetermination, pessimism, and inevitability of death (Mayo et al, 2001). The tool measures fatalism about breast cancer (Items 1-4), fatalism about screening (item 5), and fatalism about the course of cancer and death (Items 6-11). Responses for each question are yes (scored as one point), or no (scored as zero points). The maximum score is 11 points and higher scores indicate stronger beliefs in cancer fatalism. The Breast Cancer Knowledge Questionnaire, consisting of 15 questions (Appendix A-3) was derived from the Breast Health Intervention Evaluation Study, a federally funded intervention study conducted at Morehouse School of Medicine in Atlanta, Georgia. The test was used most recently with African American adult daughters of mothers with breast cancer to measure breast health and breast cancer knowledge (Callahan, 2008).

Immediately following the educational presentation, participants will be asked to complete the post-intervention breast cancer knowledge questionnaire again. Participants will be followed up in six months. At that time, the PI will re-visit the senior lunch programs and obtain a third post-intervention breast cancer knowledge questionnaire, the revised Powe Fatalism Inventory, and a questionnaire asking if participants have obtained a mammogram since the educational presentation.

Data Analysis: The three outcome variables included in the data analysis include breast cancer knowledge, fatalism, and participation in mammography screening. Descriptive statistics (means, percentages, standard deviations, and standard errors) will be computed for each variable as appropriate. Generalized estimating equations (GEE) will be used to fit the repeated measures models. GEE is very flexible with a selection of link functions and error terms capable of analyzing normal and binary outcomes. Potential project pitfalls include attrition of participants; GEE is designed to allow all available data to be used even though some subjects may not have complete data for all time periods. GEE will also be used to look at the relationship of fatalism to breast cancer knowledge over time, and to look at the relationship of knowledge and fatalism to mammography participation.

Compensation for Participants: Free lunch will be offered to participants who attend the educational presentation. Participants will be invited to take part in a raffle for a \$50 gift certificate to Vons grocery store on the day of presentation day after they have completed the pre- and post-intervention tests and fatalism inventory. Participants who complete the six month follow-up data collection will receive a \$25 gift certificate for a local store.

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Limitations of the Study: This beginning study has a number of limitations. Recruitment of participants is by convenience sampling in a small underserved area of San Diego County, so results may not be generalizable to other populations. Because of the possible sensitivity of breast-related issues among older women, participants may not be truthful in response to surveys. Because this is a one-time, brief intervention, its long-term effects will not be determined.

Risks: One of the risks may be breach of confidentiality. This will be addressed by maintenance of all study materials in a locked file cabinet accessible only to the investigator and members of her dissertation committee. Materials will be kept for 5 years, after which they will be destroyed. The study may bring about emotional distress because of the sensitivity of the topic. Contact information for mental health providers will be given to participants in the event that emotional distress occurs. Participants may become fatigued and experience difficulty concentrating or completing tests. If so, arrangements will be made to reschedule data collection at another time.

Research Plan Time Line:

The research project aims will be accomplished according to the following timeline:

Months 1,2,3:

- Schedule reservation dates with senior lunch sites for educational presentation
- Obtain approval to cover cost of lunch for participants who attend the presentation
- Purchase incentives
- Obtain copy of video

Months 4,5,6:

- Develop educational presentation and data collection tools:
 - Create presentation script
 - Review and approval of video and script by PI's mentor Dr. Mary Jo Clark
 - Obtain permission to use the BRIE Breast Cancer Knowledge questionnaire
 - Create mammography participation questionnaire, sign in sheet, and standardized informed consent
- Develop database

Months 7,8,9:

- Intervention:
 - Implement 2 educational presentations per site, every other week for a total of 6 presentations.
 - Code data
- Data entry:
 - Pre-intervention demographic questionnaire
 - Pre- and post-intervention Breast Cancer Knowledge Questionnaire
 - Pre-intervention revised Powe Fatalism Inventory

Months 10,11,12:

- Preparation for post- intervention follow up:
 - Schedule post intervention follow-up visits at church site
 - Distribute flyers of post intervention dates
 - Prepare annual report to USD Institutional Review Board

Months 13, 14, 15:

- Post-intervention follow-up visits
 - Conduct 2 follow-up visits per site, for a total of 6 follow up visits
 - Schedule individual visits for participants who were unable to attend follow up sessions
- Data entry:

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- Post-intervention revised Powe Fatalism Inventory, mammography participation questionnaire, post-intervention Breast Cancer Knowledge Questionnaire

Months 16, 17, 18:

- Data analysis:
 - Analyze data using GEE
 - Prepare manuscript outline

Months 19,20, 21:

- Prepare manuscript:
- Prepare final report to CBCRP:

Months 22, 23, 24:

- Submit final manuscript
- Submit final report to CBCRP
- Submit final report to USD Institutional Review Board

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HUMAN SUBJECTS

1. Detailed description of the proposed involvement of human subjects in the project: The proposed research study will take place at 3 senior lunch programs at churches and senior community centers in underserved areas of San Diego County and will involve women over the age of 65, who participate in the senior lunch programs at the sites. Prior to human subject recruitment, approval to conduct the study will be obtained through the University of San Diego's Institutional Review Board. Women who agree to participate in the study will be asked to fill out a demographic questionnaire, a breast cancer knowledge test, and a cancer fatalism inventory prior to watching a 13 minute educational video about breast cancer and mammography screening. Following the video, a discussion led by a nurse practitioner experienced in breast cancer detection and community health promotion will be conducted in which participants will be encouraged to ask questions and information will be provided about free or low cost mammograms in the area. Following the educational presentation, participants will be asked to fill out a second breast cancer knowledge test. Free lunch will be provided for participants who agree to participate in the educational presentation, and a raffle for a gift certificate to a local grocery store will take place for participants who complete all forms, tests, and inventories. Study participants will be contacted again in 6 months at the lunch sites, at which time they will be asked to fill out a second fatalism inventory and another breast cancer knowledge test, and asked if they have obtained a mammogram since participating in the educational presentation. Participants who, at the six-month follow up, complete the post intervention fatalism inventory, knowledge test, and mammography participation questionnaire will be compensated with a gift certificate to a local grocery store.

2. Characteristics of the subject population, especially underserved and minority populations: Inclusion criteria for subjects includes women over 65 years of age, non-homebound, who attend senior lunch programs at churches or senior community centers located in underserved areas of San Diego County. Study participants will include women with or without a personal or family history of breast cancer. Women will be required to comprehend English. Literacy is not necessary, since assistance with answering questions and inventories will be offered for women who have difficulty reading or writing English. The lunch program locations for population recruitment were selected in underserved areas of San Diego County because groups of low income and minority older women would likely be accessible. The three different lunch program location sites will permit for a larger population sample, representing older women from different underserved areas of San Diego County who are not homebound.

3. Identify the sources of research material specimens, records or data: Data would be obtained through tests of breast cancer knowledge and responses to the revised Powe Fatalism Inventory (rPFI) prior to participating in an educational presentation conducted at the lunch program site during a regularly scheduled senior lunch session, as well as at 6 months following the presentation event. The collected data will be used for the sole purpose of the proposed research project.

4. Describe the plans for recruiting subjects and documenting consent: The research project will be explained to groups of older women during a scheduled lunch session by the PI. Those who wish to participate in the study will meet with the PI individually. At that time, the PI will review the consent form and obtain two consents; one for the participant to take home and another for the PI to keep in a locked file. Participants will receive written and verbal information about the project's purpose, the voluntary nature of participation and ability to stop at any time, confidentiality of the data, and potential risks and benefits of participation prior to agreeing to participate in the study.

5. Describe any potential risks —physical, psychological, social, legal, or other: Potential risks of the study include breach of confidentiality and the possibility of emotional distress due to the sensitivity of the topic. There might be a risk for fatigue. Due to lower level of acculturation in minority populations, there is a risk that participants might have difficulty reading or comprehending survey questions.

6. Describe the procedures for protecting against, or minimizing, any potential risks: Contact information for mental health providers will be given to participants in the event that emotional distress occurs. Participants will be encouraged to take their time completing tests and inventories, and all measures will be

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taken to provide a comfortable, quiet environment with plenty of time allowed for participants to answer the questions without feeling rushed. Participants will be encouraged to ask questions if they encounter difficulty comprehending questions. If participants become fatigued while completing the tests and inventories, arrangements will be made to reschedule data collection. To ensure confidentiality, data measures will be separated from consent forms and coded with an identifying number, and access will be limited only to people involved directly in the research project, including the PI, the PI's mentor, and other members of the PI's dissertation committee. Data will be analyzed using generalized estimating equations (GEE), and codes without names will be used in the database. Consent forms will be written in keeping with the requirements of the University of San Diego's Institutional Review Board. All materials and data collected will be kept in a locked file for a minimum of 5 years, after which they will be destroyed.

7. Discuss why the risks are reasonable in relation to the anticipated benefits: The findings from the proposed research project will enhance future development of health interventions and programs to increase mammography participation in older women, reducing age-related disparities in early breast cancer detection in this population. Individual women participants may also benefit from participating in mammography and potential earlier diagnosis of and better prognosis for breast cancer. Considering the low level of risk involved in the study and the measures to minimize risk noted above, the potential benefits of the proposed research project outweighs the risks.

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Briefly describe the facilities and resources (e.g., laboratory space, core facilities, major equipment, access to populations, statistical resources, animal care, and clinical resources) that are needed and are available for successfully carrying out the proposed research. Make sure all of the research needs described in the research plan are addressed in this section. Describe resources supplied by subcontractors and those that are external to the institution.

Access to participants will be through several churches and social service agencies in the San Diego area that provide senior lunch programs. Space for the educational presentation and projection equipment to show the video will be available at each site.

Statistical analysis and data base development assistance are available through the University of San Diego, School of Nursing. Similarly, computer access is available through the School for data analysis.

Locked data storage space will be available in the PI's home.

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PROGRAM RESPONSIVENESS

☐ The Community Impact of Breast Cancer
Etymology and Prevention

☐ Biology of the Breast Cell
☒ Detection, Prognosis and Treatment

Explain how the research is responsive to the priority issue selected: The proposed interventional study addresses the detection, prognosis, and treatment of breast cancer to promote mammography screening and early breast cancer detection among older women. Although increased age is the most common risk factor for developing breast cancer (American Cancer Society, 2009), older women are less likely than younger women to obtain mammograms. According to the most recent Medicare statistics, from January 2003 thru December 2004, only 50.5% of eligible women over age 65 residing in the state of California obtained a mammogram in a 2 year period (Centers for Medicare and Medicaid Services (CMS), 2006). Early detection of breast cancer by mammography increases survival rates and quality of life by allowing a broader range of treatment options. Further research regarding barriers to mammography participation among older women, including lack of awareness and health beliefs, have been identified in the literature as sorely needed to eliminate the unequal burden of breast cancer in this population. In a study conducted by Giuliano, Liu, & Wood (2004), 39% of older women who reported never receiving a mammogram believed it was not necessary. In a study conducted to determine psychosocial correlates of mammography screening in older African American women, it was found that women who felt more strongly that mammography screening was beneficial were more likely to have had a mammogram in the prior year (D'Agostino, Farmer, Jackson, & Reddick, 2007). Another significant psychosocial barrier to mammography participation in older women is fatalistic views about cancer. The proposed research study seeks to determine the effects of a breast health awareness program on knowledge of and fatalistic attitudes toward cancer screening in older women.

Part II. Indicate the Award Type for this application.

☐ IDEA
☐ IDEA – Junior Investigator
☐ Joining Forces Conference Award

☐ Postdoctoral Fellowship
☒ Dissertation
☐ Translational Research Award

Explain how both the research and PI are responsive to the award type selected. The P-I is a doctoral candidate in the PhD in Nursing program at the Hahn School of Nursing and Health Science, University of San Diego. She has a clinical nursing background in oncology care. Completion of the research project will enable the P-I to incorporate her clinical nursing background into breast cancer-related research and meet the dissertation requirements for the PhD, including writing 3 articles for publication. Dissemination of the research project findings will comprise one of the three articles. The mentor, Dr. Mary Jo Clark, is the chairperson for P-I's dissertation committee. The mentor is an experienced community health researcher and has experience conducting breast cancer research with under-served women. She has completed a pilot CRC project funded by CBCRP, and is currently applying for an intervention study to improve mammography screening among Thai women in Southern California.

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DISTINCTION FROM OTHER FUNDING

The proposed study addresses barriers to mammography screening in underserved older women. Although several CBCRP funded studies address early detection barriers in minority women, there are limited CBCRP funded studies addressing breast cancer screening in older women, including breast cancer knowledge and beliefs, which significantly determine mammography participation among older women.

The proposed research study builds on the PI's mentor, Dr. Mary Jo Clark's, CBCRP- funded pilot CRC study "Factors Influencing Breast Cancer Screening among Older Thai Women" to increase mammography screening and decrease breast cancer related mortality rates among older women in underserved areas of San Diego County. In Dr. Clark's study of Thai women in southern California, older women (>70 years) believed that mammography was not necessary but were more likely than younger Thai women to obtain mammograms. In the proposed research study, the literature review indicates that older women, in general, are less likely than younger women to participate in mammography screening. Limited existing research addressing breast cancer screening behaviors and barriers among Asian women and older American women are associated with disparities in early breast cancer detection and prevention among these vulnerable populations. As the elderly population in the United States continues to increase, further studies addressing breast cancer screening barriers among older women are required to enhance development of public health recommendations and interventions to increase mammography participation.

Unlike the mentor's currently proposed study to increase mammography use among Thai women being submitted to CBCRP, the proposed dissertation research study will address fatalism; a commonly reported psychosocial barrier associated with mammography participation among older women. Specifically, the study aims to examine the relationship between fatalistic perceptions about breast cancer and mammography participation among older women. Fatalism is defined as a belief that events are fixed in advance for all time in such a manner that humans are powerless to change them (Fatalism, n.d.). In older women, fatalism has been suggested as an independent predictor of participation in cancer screening (Baron-Epel, Friedman, & Lema, 2009). There is a need to identify interventions that modify perceptions of cancer fatalism and promote screening in the older population. The proposed dissertation research study aims to determine the relationship between fatalism and mammography participation among older women.

The potential impact of the proposed project will lie in earlier diagnosis of disease in older women through improved screening participation. Earlier diagnosis will permit earlier treatment at less personal and societal cost and result in long-term reduction in breast cancer mortality among older women in San Diego County.

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ADDITIONAL CRITERIA

Focus on Underserved Populations: The proposed study is focused on reducing age-related disparities in early breast cancer detection among older women, and underserved populations in breast cancer screening. According to the most recent Surveillance, Epidemiology, and End Results (SEER) statistics, breast cancer diagnosed in older women tends to be found at more advanced stages, contributing to documented poorer survival rates (SEER, 2009). Decreased participation in mammography screening among older women is linked to advanced breast cancer disease at time of diagnosis. Early breast cancer detection by routine mammography screening leads to earlier stage diagnosis, less radical surgery, less disability, better quality of life, and increased survival rates (Giuliano, Liu, & Wood, 2004). According to the literature review, older women have been underrepresented in breast cancer research studies. Limited knowledge on risks and benefits of mammography screening among older women has resulted in a lack of health care provider recommendation, decreasing older women's motivation to participate in mammography screening. The increase in the elderly population in the United States provides a soaring need for further breast cancer research involving older women that would determine appropriate interventions to optimize mammography screening among this population. The proposed research study addresses the needs of underserved and under-represented older women through exposure to an educational presentation to increase breast cancer knowledge and decrease fatalistic perceptions about breast cancer. Both lack of knowledge and fatalistic perceptions of breast cancer have been reported in the literature as barriers to mammography participation among older women. The proposed research project aims to determine if the educational intervention increases mammography participation among older women by eliminating these barriers through improved breast health awareness.

Involvement of Advocates in the Research: The PI is a nurse practitioner in a community clinic, where she engages in breast health awareness presentations at clinic health education programs to promote breast cancer screening among underserved and older women. The PI also participates in medical mobile unit homeless outreach services through the clinic to provide cancer screening to homeless women in San Diego County. The San Diego Susan G. Komen Advocacy Alliance's most recent position paper on Health Reform calls on congress to address issues that would eliminate disparities in breast cancer screening among underserved women living in underserved areas of San Diego, including elimination of copayments or deductibles for preventive services such as mammograms. Among low-income older women with Medicare, even a small co-payment can reduce mammography participation. Disproportionate breast cancer burdens fall on underserved populations who lack access to mammography screening due to barriers. The PI intends to participate in the Susan G. Komen Advocates in Science. As a breast cancer research advocate, the PI intends to address the needs of underserved older women to ensure that information about breast cancer detection is disseminated to vulnerable populations, such as the elderly and the homeless, in a culturally and educationally sensitive manner. The PI will continue to advocate for more medical mobile units for mammogram services to eliminate transportation and immobility barriers often encountered by older women, preventing them from participating in mammography screening. Serving in the Advocates in Science Program will also allow the PI to translate current breast cancer research into public health as a clinician in San Diego community clinic settings. An application for entering the Advocates in Science program will be submitted by the PI in the Spring of 2010. If accepted to the advocacy program, the PI will serve a 2 to 3 year term.

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CAREER PLAN

The PI is a doctoral student transitioning from an extensive clinical nursing background into a novice nurse researcher. The PI has 8 years experience working as an oncology staff nurse in several acute care cancer facilities located in San Diego County. The PI is a graduate of the Master's Nurse Practitioner/Geriatric Subspecialty program from the University of San Diego, Hahn School of Nursing and Health Science and has been practicing since 2003 as a Nurse Practitioner at a community clinic in an underserved area of San Diego County.

In her role as a Nurse Practitioner, the PI has extensive clinical experience working with underserved populations, particularly older women. One of her clinical roles is working in the women's health clinic, where she performs annual exams, including clinical breast exams and arranging for mammography screening appointments. She is also a health care provider in the organization's bimonthly breast clinic, where women with abnormal clinical breast exams or imaging are monitored closely. The PI is fluent in Spanish and is responsible for providing and coordinating breast health awareness education during clinical exams to Spanish-speaking women. The PI became interested in breast cancer research after several years of interacting with underserved women in a clinical setting and identifying lack of breast health awareness among these women in the organization's women's and breast clinic. One of the needs found in her clinic setting was providing culturally and linguistically relevant breast health education to older minority women. During her literature review, the PI was able to identify barriers associated with lack of participation in mammography screening, including lack of knowledge and fatalism, both of which were noticeable among her clientele.

The current research project will provide an opportunity for the PI to develop as a breast cancer researcher in community health. The project focuses on barriers to mammography screening encountered by underserved older women, particularly those, such as lack of knowledge and fatalism, that could be modified by appropriate interventions. The project will build on current theories of cancer fatalism, a common belief found primarily in minority women and women with limited education and associated with decreased participation in cancer screening, including mammography. The project will also improve both the PI's ability to translate study findings into clinical practice in her role as a community clinic health care provider, and her ability to motivate underserved women to participate in cancer screening.

The PI's long term plans for a breast cancer research career include post doctoral work in community health. Specifically, the PI is interested in community program development for early cancer detection and prevention in underserved and under-represented women. Because the proposed project addresses cancer fatalism, a common predictive indicator associated with decreased cancer screening participation found in underserved women, project study findings may potentially identify future research questions to be addressed once the project is completed. The PI wishes to build on the current body of knowledge on cancer fatalism by identifying strategies to better understand fatalistic views among underserved women and develop appropriate educational interventions for use in community clinics.

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BIOGRAPHICAL SKETCH and OTHER SUPPORT

Name: Ibarra, Martha

Role in Project: Principal Investigator

A. Education:

<u>Institution</u>	<u>Degree</u>	<u>Year(s)</u>
National University, San Diego	Bachelor of Science, Nursing	December 1997
University of San Diego	Masters of Science, Nursing	May 2000
University of San Diego	Doctor of Philosophy in Nursing	2005 to present

B. Research and professional experience: List positions in chronological order.

<u>Organization</u>	<u>Title</u>	<u>Year(s)</u>
Family Health Centers of San Diego	Nurse Practitioner	June 2003 to present
Michael Markopolous, M.D., Inc.	Nurse Practitioner	12/2002 to 08/2003
Comprehensive Health Centers	Nurse Practitioner	04/2002 to 11/2002
UCSD Medical Center	Registered Nurse	10/1998 to 04/2002
Sharp Memorial Hospital	Registered Nurse	10/1997 to 10/1998
Scripps Mercy Hospital	Registered Nurse	08/1995 to 04/1997
USC/LAC Medical Center	Registered Nurse	12/1994 to 09/1995

C. Publication

None

D. Other grant support:*Nurse Faculty Loan Program*

University of San Diego, Hahn School of Nursing

2009-2010 school year

Tuition Fees

\$15,798

University of San Diego Graduate Grant

Books and Supplies

\$3,500

Federal Unsubsidized Stafford loan

Living expenses

\$9,755

Federal Subsidized Loan

Living expenses

\$1,526

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MENTOR PROFILE and TRAINING PLAN**TO BE COMPLETED BY THE MENTOR**

Limit is 2 pages

(Instructions)

Mentor Profile

A. Provide your mentoring history and current activity in training young scientists. How many graduate students, medical students, and postdoctoral fellows are under your direction? Provide examples of prior trainees and their current career positions.

In the last 20 years, Mary Jo Clark, PhD, RN has supervised or served on more than 30 dissertation committees for PhD students in nursing at the Hahn School of Nursing and Health Science, University of San Diego. Dr. Clark is currently chairing three dissertation committees and is serving as a committee member on two others. Most of her graduates are employed in nursing faculty positions in which they continue their research on a part-time basis. Others are CEOs or Chief Nurse Officers of local hospital systems who use their research skills in assessing the quality of patient care in their institutions. Still others are employing their research skills in policy development at state and national levels. One graduate, whose committee she served on, was employed as the research director for a major Naval health institution prior to her retirement from the Navy Nurse Corps. She currently supervises graduate students in research at Uniformed Services University and continues with her own major research interest in breast cancer.

In addition, Dr. Clark is currently supervising translational research projects for 8 Doctor of Nursing Practice students and has provided consultation for 8 additional translational projects, two of which address breast cancer-related research.

B. Describe the infrastructure available in your immediate research environment, department and institution for training in breast cancer research (e.g., collaborators, research and clinical networks, model systems in current use). Highlight your recent breast cancer publications, grant funding, and/or collaborations with other breast cancer researchers and advocacy/community groups.

Although not a medical center campus, the University of San Diego and the Hahn School of Nursing and Health Science have a variety of connections with local health care institutions, including 5 major health care systems in the San Diego area, as well as a wide-spread system of community clinics and other agencies with interests in breast cancer research. In addition, Dr. Clark has a personal link with THAIS, Inc., a community organization in Los Angeles with which she is involved in breast cancer awareness and screening promotion initiatives. Dr. Clark has been co-PI on a CBCRP-funded CRC pilot project with THAIS, Inc., and is currently involved in developing a proposal for a CRC full award. The prior study resulted in one publication and three regional/national presentations thus far, with another publication in the works. Dr. Clark also has a wide variety of other experience (with resulting publications) in conducting community-based research with elderly, ethnic, and underserved populations. Some of the areas of focus include menopause in Japanese women, reminiscence among elderly Taiwanese residents, and assessment of community health needs in a low-income multi-ethnic community in San Diego county. Breast-cancer publications/presentations are as follows:

Clark, M. J., & Natipagon-Shah, B. (2008). Thai American women's perceptions regarding mammography participation. *Public Health Nursing*, 25, 212-220.

Natipagon-Shah, B. & Clark, M. J. (2008). Unlearning the lesson on breast cancer screening. A video script for NurseTV.com on the hazards of substituting breast self-examination for mammography and clinical breast examination.

Factors Influencing Mammography Among Older Thai Women. Poster presentation at the 41st Annual Communicating Nursing Research Conference, Western Institute of Nursing, Garden Grove, CA, April 19, 2008. (with B. Natipagon-Shah)

Factors Influencing Breast Cancer Screening in Thai American Women. Poster Presentation. California Breast Cancer Research Program Symposium. September 7, 2007, Los Angeles. (with B. Natipagon-Shah)

Principal Investigator:

Ibarra, Martha I

BIOGRAPHICAL SKETCH AND OTHER SUPPORT

Limit is 4 pages per person listed as Key Personnel.

This form is required for all applications.

The corresponding NIH form may be substituted

This form is used for the peer review and the programmatic review.

Name: Mary Jo Clark

Role in Project: Dissertation Mentor

A. Education: Begin with baccalaureate and end with the most recent, including postdoctoral training.

Institution	Degree	Year(s)
University of San Francisco	BSN	1963-1967
University of California, Los Angeles	Pediatric Nurse Practitioner	1973
Texas Women's University	MSN	1976-1979
University of Texas at Austin	PhD	1985-1988

B. Research and/or Professional Experience: List positions in chronological order.

Organization	Title	Year(s)
U.S. Peace Corps	Volunteer	1967-1969
Los Angeles County Hlth Dpt	Public Health Nurse	1969-1976
Los Angeles County Hlth Dpt	Pediatric Nurse Practitioner/PHN	1973-1976
East Tennessee State University	Instructor/Asst. Professor	1976-1982
Medical College of Georgia	Assistant Professor	1982-1986
University of San Diego	Asst./Assoc./Professor	1986-present
University of San Diego	Associate Dean	1995-2003
University of San Diego	Interim Dean	2002-2003

C. Publications: See instructions.

- Clark, M. J., & Natipagon-Shah, B. (2008). Thai American women's perceptions regarding mammography participation. *Public Health Nursing, 25*, 212-220.
- Chao, S.-Y., Lan, Y.-H., Tso, H.-C., Chung, C.-M., Neim, Y.-M., & Clark, M. J. (in press). Predictors of psychosocial adaptation among elderly residents in long-term care settings. *Journal of Nursing Research*
- Chao, S.-Y., Chen, C.-R., Liu, H.-Y., & Clark, M. J. (2008). Meet The Real Elders: Reminiscence Links Past and Present. *Journal of Clinical Nursing, 17*, 2647-2653.
- Natipagon-Shah, B. & Clark, M. J. (2008). Unlearning the lesson on breast cancer screening. A video script for NurseTV.com on the hazards of substituting breast self-examination for mammography and clinical breast examination.
- Clark, M. J. (2008). Fun in the sun: Preventing skin cancer. A video script for NurseTV.com on the importance of and strategies for preventing skin cancer by individuals and in school settings.
- Clark, M. J. (2008). *Community health nursing: Advocacy for population health* (5th ed.). Upper Saddle River, NJ: Pearson Prentice Hall.
- Clark, M. J. (2008). *Community Assessment Reference Guide*. Upper Saddle River, NJ: Pearson Prentice Hall.
- Chen, J.-Y., & Clark, M. J. (2007). Family function in families of children with Duchenne muscular dystrophy. *Family & Community Health, 30*, 296-304.

Principal Investigator:

Ibarra, Martha 2

- Chao, S.-Y., Liu, H.-Y., Wu, C.-Y., Jin, S.-F., Chu, T.-L., Huang, T.-S., & Clark, M. J. (2006). The effects of group reminiscence therapy on depression, self-esteem, and life satisfaction of elderly nursing home residents. *Journal of Nursing Research*, 14, 36-44.
- Clark, M.J., Cary, S., Diemert, G., Ceballos, R., Sifuentes, M., Atteberry, I., Vuc, F., & Tricu, S. (2003). Involving communities in community assessment. *Public Health Nursing*, 20, 456-63.
- Clark, M.J., Noji, A., & Curran, C. (2000). Evidence-based community health nursing practice. *Sapporo Medical Journal*, 69(suppl.), 14-21.
- Clark, M. J., Curran, C., Noji, A. (2000). The effects of community health nurse monitoring on hypertension identification and control. *Public Health Nursing*, 17(6), 452-459.
- Clark, M.J., Schmitz, S., Conrad, A., Estes, C., Healy, M. M., & Hiltibidal, J. (1999). The effects of an intervention campaign to enhance seat belt use on campus. *Journal of American College Health*, 47, 277-280.

Presentations (breast cancer related presentations only)

- 2008 Mammography Screening among Thai Women in Southern California, presentation to USD MSN students, MSNC 511, December 9, 2008.
- Factors Influencing Mammography Among Older Thai Women. Poster presentation at the 41st Annual Communicating Nursing Research Conference, Western Institute of Nursing, Garden Grove, CA, April 19, 2008.
- 2007 Dimensions Model and Mammography Screening among Thai Women. Paper. American Public Health Association Annual Meeting. November 6, 2007. Washington, DC. (with B. Natipegon-Shah)
- Prevalence of Factors Influencing Mammography Screening among Thai Women. Poster Presentation. American Public Health Association Annual Meeting. November 5, 2007, Washington, DC. (with B. Natipegon-Shah).
- Factors Influencing Breast Cancer Screening in Thai American Women. Poster Presentation. California Breast Cancer Research Program Symposium. September 7, 2007, Los Angeles. (with B. Natipegon-Shah)

D. Other grant support: See instructions.

Grant Proposal Preparation Funding

Completed November 2009, University of San Diego, Hahn School of Nursing and Health Science
Coordinator of Community Action Group efforts to develop current CBCRP proposal, 5% time, (\$7,500).
This grant was used to support the activities of the CAG in development of the proposal currently being submitted for CBCRP consideration. No overlap.

No other grant support

Principal Investigator Ibarra, Martha

Prevalence of Factors Influencing Mammography Screening among Thai Women. Poster Presentation. American Public Health Association Annual Meeting. November 5, 2007. Washington, DC (with B. Natipagon-Shah).
Dimensions Model and Mammography Screening among Thai Women. Paper. American Public Health Association Annual Meeting. November 6, 2007. Washington, DC. (with B. Natipagon-Shah)

The University of San Diego and the Hahn School of Nursing and Health Science also have the support of an Office of Sponsored Programs and a part-time statistical consultant, as well as computer access and support for data base development, data storage, and data analysis.

Training Plan

Describe in detail your mentoring activities planned for the applicant. How much time/week on average will you and others spend supervising the current project and student/fellow? Describe any outside collaborations planned to develop the applicant's repertoire of skills during the course of this project. Besides yourself, who will train the student/fellow? How will the trainee be encouraged and provided an opportunity to interact with advocates?

Dr. Clark will spend approximately 2 hours per week with the applicant discussing the project and overseeing IRB submission and data collection, analysis, and interpretation activities. She will review with the applicant the proposed content for the education presentation as well as the presentation venue and approaches to be sure that they are culturally and linguistically appropriate for the target population. In addition, Dr. Clark will be working closely with the applicant in the development of the required three manuscripts related to the dissertation project. Given the amount of input anticipated putting into this effort, Dr. Clark will be named as second author on the resulting publications.

Other members of the student's dissertation committee, who have expertise in community-based research, services to elderly populations, and research with underserved groups, will also work closely with the applicant. The applicant will also have access to the services of a School of Nursing contracted statistician to assist with data base development and statistical analysis of study data. In addition, the applicant will be invited to participate in research team meetings related to Dr. Clark's own project testing an educational intervention to improve mammography screening participation in the Thai population in southern California. Although the target population for this study differs from that of the applicant, there are a number of similar factors influencing screening participation that may provide learning experiences for the applicant. She will also have the opportunity to observe activities related to data analysis and interpretation of findings that may prove useful in carrying out her own project.

Co-Principal Investigators:

Ibarra, Martha

BUDGET SUMMARY

This form is used for the peer review and the programmatic review.

Enter the requested direct cost budget for each year for each institution requesting a direct award (or subcontract). Be sure that the requested terms and costs fit the limitations for the award type.

BUDGET CATEGORIES:		FY 2009-2010 YEAR 1	FY 2010-2011 YEAR 2 ⁷
PERSONNEL ¹		\$34,936	\$36,900
CONSULTANT & CONTRACTUAL ²		N/A	N/A
SUPPLIES and EXPENSES		\$2,494	\$100
EQUIPMENT		N/A	N/A
TRAVEL	CBCRP SYMPOSIUM ³	\$500	N/A
	PROJECT-RELATED ⁴	\$85	N/A
	SCIENTIFIC MEETINGS ⁵	N/A	\$2000
DIRECT COSTS		\$37,995	\$38,000
INDIRECT (F&A) COSTS ⁶		N/A	N/A
YEARLY TOTAL COSTS		\$37,995	\$38,000
ENTIRE PROJECT:		TOTAL DIRECT COSTS \$75,995	
		TOTAL F&A COSTS N/A	
		TOTAL COSTS \$75,995	

1. Name all individuals to be supported by the grant and percent effort on the "Budget Justification & Facilities" form.
2. Detailed Contractual budgets and letters of collaboration should be included in the Appendix.
3. Any requested equipment items must be >\$5,000 and identified on the "Budget Justification & Facilities" form
4. \$400/yr is recommended. List and explain on the "Budget Justification & Facilities" form
5. Maximum of \$2,000/year per co-PI
6. On the Budget Justification Form indicate whether the indirect rate is based on a DHHS Agreement, established by another source, or is based on the CBCRP default rate of 25%.
7. Pilot award can include six months in Year Two for a total of 18 months.

For all non-UC institutions (with approved rates) provide the following information:

Currently approved F&A rate: 54.6% Period of approval for this rate: Provisional: 7/1/10 to 6/30/11
 Predetermined: 7/1/06 to 6/30/10

Are you expecting an F&A rate adjustment by July 1, 2009? Yes X No

Principal Investigator: Ibarra, Martha

BUDGET JUSTIFICATION and FACILITIESLimit is 2 pages**A. Budget Justification**

Name each person to be supported by this grant, their percentage FTE committed to the project, and their role in the project. Explain the need for contractual arrangements, pieces of equipment, major supply items, and project-related travel. Sub-contract budget details and letters of collaboration should be placed in the appendix.

Personnel	Martha Ibarra	80%	PI	Amount
Year one				
	Salary stipend			\$26,171
	Benefits (33.49%)			<u>\$8,765</u>
	Total			\$34,936*
Year two				
	Salary stipend			\$26,893
	Benefits (33.49%)			<u>\$9,007</u>
	Total			<u>\$35,900*</u>
Project total				\$70,836

* This is a working mother of a minor child who will have to reduce her regular nursing employment to 20% time in order to devote 80% to the dissertation project. Even increasing the stipend amount to the maximum available under the \$38,000 yearly maximum, she will barely be able to survive. Tuition and books are covered under funds available from the Nurse Faculty Loan Program and she is also receiving federal Stafford Loan funds, but these do not offset the loss of a major portion of her nursing income. For these reasons, the university will allow a stipend over the federal cap for graduate students.

Supplies and expenses

Item	Amount
Gift card stipends for participants (60 @ \$25 each)	\$1,500
Participation handouts (chapstick, hand sanitizer) \$3/person x 60	\$180
Knowledge pre/post-test (2 Pages x 120 copies @ \$0.10/page)	\$24
Fatalism Inventory (2 page x 120 copies @ \$0.10/page)	\$24
Demographic data forms (1 page x 60 copies @ \$0.10/page)	\$6
Lunch for participants (\$6 per person x 60 x 2 sessions initial and 6-month follow-up)	\$720
Educational supplies (posters, handouts, etc.)	\$40
Report preparation	\$50
Poster/handout preparation for scientific meetings	<u>\$50</u>
Total:	\$2,594

Travel

CBCRP symposium	\$500
Project related travel to senior lunch sites	\$65
Scientific meetings	<u>\$2,000</u>
Total:	\$2,565
Overall project total:	\$75,995

B. Facilities

Running head: FATALISM REVISITED

Fatalism Revisited

Martha A. Ibarra, PhD, RN, ANP

Logan Heights Family Health Centers of San Diego

Mary Jo Clark, PhD, RN

University of San Diego

Author Note

Martha A. Ibarra, Adults Department and Women's Clinic, Logan Heights Family Health Centers of San Diego; Mary Jo Clark, Hahn School of Nursing and Health Science, University of San Diego.

Correspondence concerning this article should be addressed to Martha A. Ibarra, Adults Department, Logan Heights Family Health Centers, 1809 National Ave, San Diego, CA 92113.

Email: marthai@fhcsd.org;

Abstract

Purpose/Objectives: To examine theoretical perspectives on cancer fatalism, provide an overview of related ethnic and cultural roots, and examine the implications of fatalism for health care delivery and research.

Data Sources: Research articles, published journal articles and data from the National Cancer Institute, the American Cancer Society, and health care related internet sources on cancer fatalism and minorities. Literature sources included CINAHL, PubMed, and PsychInfo through November 2011.

Data Synthesis: Minority populations are increasing and will account for more than half of the U.S. population by the year 2050. Minority and underserved populations bear a greater cancer burden than the rest of the nation. Cancer fatalism has been recognized as a significant cultural barrier to obtaining cancer screening among minorities. Inconsistent findings of cancer fatalism in diverse populations have been attributed to different conceptual definitions of fatalism, poor validity of fatalism scales, and differences in study methodology. Methodological pitfalls in cancer fatalism studies have resulted in several misconceptions related to cancer fatalism among minority groups.

Conclusions: Research studies consistently demonstrate that cancer fatalism is a socio-cultural belief associated with poor acceptance of cancer screening tests among minorities. Lack of consistent conceptual frameworks to evaluate and interpret cancer fatalism has resulted in limited development of effective strategies to eliminate cancer disparities among minorities.

Implications for Nursing: Additional research in cancer fatalism is needed to clarify theoretical frameworks and to improve the validity of cancer fatalism measures, analysis, and interpretation.

Fatalism Revisited

Minority populations in America are increasing and will account for more than half of the U.S. population by the year 2050 (Goss et al., 2009). In 2010, the Hispanic population accounted for more than half of the 27.3 million increase in the total U.S. population, and the Asian population had the second largest population increase, growing from 10.2 million in 2000 to 14.7 million (Humes, Jones, & Ramirez, 2011). The Trans-HHS Cancer Health Disparities Progress Review Group (2004) reported that within the United States, “minority and underserved populations bear a greater cancer burden than the rest of the nation, and are significantly more likely to be diagnosed with and die from preventable cancers; be diagnosed with late-stage disease for cancers detectable through screening in the early stage; receive either no treatment or treatment that does not meet currently accepted standards of care; die of cancers that are generally curable; and suffer from cancer without the benefit of pain control and other palliative care” (p. 2). Due to the increase in minorities and their vulnerability to cancer disparities, it is anticipated that from 2010 to 2030 there will be a 99% increase in incidence of cancers for minorities, compared with a 31% increase for whites (Smith, Smith, Hurria, Hortobagyi, & Buckholz, 2009).

Cancer Incidence in Minorities

Since the early 20th century, cancer disparities related to socioeconomic and racial/ethnic inequalities have been documented in several parts of the world, including the United States (Krieger, 2005). The National Cancer Institute (NCI) defined cancer disparities as differences in cancer incidence, prevalence, mortality, and survivorship that exist among specific population groups in the United States (NCI, 2008).

Although cancer disparities are prominent among minorities in general, variations in incidence and mortality have been noted within ethnic minority groups. For example, figures from the American Cancer Society (ACS, 2008) indicate that African Americans have higher cancer related incidence and mortality rates than any other racial or ethnic group. African American women have the highest breast cancer mortality rates among all ethnic groups (Sheppard, Davis, Boisvert, Jenings, & Montalvo, 2011). Incidence and mortality rates for cancers associated with infection (including uterine, cervical, liver, and stomach cancers) are higher in Asian Americans and Hispanics, especially among first generation Hispanic immigrants (ACS, 2009). Asian Americans and Pacific Islanders account for the highest incidence and mortality rates among all racial and ethnic groups for liver and stomach cancer in both men and women (ACS, 2008).

Cancer Screening in Minorities

Cancer screening and early cancer detection have been shown to reduce cancer-related mortality (ACS, 2012). Minorities and underserved populations are less likely to participate in cancer screening, more frequently present with advanced disease at the time of diagnosis, and continue to have higher cancer related mortality compared to the rest of the nation (ACS, 2009). Advances in treatment and early cancer detection resulted in a 14% decrease in cancer-related mortality in the United States from 1991 to 2004; however, minorities and underserved populations have not benefitted to a similar degree (Ward et al., 2008). In part, this may be because racial/ ethnic minorities and underserved populations living in poverty face many obstacles to obtaining services such as cancer screening and early detection, as well as access to high quality cancer treatment (Goss et al., 2009).

Fatalism as a Possible Explanation

Some research findings have linked socio economic barriers, such as poverty and lower education levels, with decreased participation in cancer screening (Freeman, 1989). Powe and Johnson (1995) argued that, in addition to economic barriers, cultural values and health beliefs contribute significantly to decreased participation in cancer screening among minority groups. Fatalism is one such cultural belief.

Researchers have identified fatalism as a significant health belief and cultural barrier to seeking health care among populations with lower levels of education or income and members of ethnic minority groups (Brooks, Hamilton, & Powe, 2006). Fatalistic attitudes have been correlated with unwillingness to change behavior and with a variety of negative health outcomes (Keeley, Wright, & Condit, 2009). These findings prompted subsequent studies to examine the significance of fatalism in explaining cancer disparities among minorities and underserved populations (Drew & Schoenberg, 2011; Gregg & Curry, 1994), including African-Americans (Finnie & Powe, 2003), Chinese women (Straughan & Seow, 1998), Hispanics (Florez et al., 2009), and underserved White subpopulations living in rural Appalachia (Drew & Schoenberg, 2011).

The influence of fatalism on early cancer detection and screening has been noted to vary across different minority groups. Possible explanations for inconsistent findings regarding fatalism's role as a barrier to cancer screening may derive from methodological pitfalls. These include varied operational definitions of cancer fatalism, lack of explicit theoretical frameworks, and limited evidence of construct validity and reliability for scales used to measure fatalism (Abraido-Lanza et al., 2007; Espinosa de los Monteros, & Gallo, 2010). These methodological concerns have raised questions of whether previous findings related to cancer fatalism are useful

in developing culturally appropriate public health programs to eliminate cancer health disparities. The purpose of this article is to examine theoretical perspectives on cancer fatalism, provide an overview of ethnic and cultural roots associated with cancer fatalism, and examine the implications of fatalism for health care delivery and research.

Fatalism Defined

Different operational definitions of fatalism have been cited in the literature including “the belief that death is inevitable when cancer is present” (Finnie & Powe, 2003, p. 454) and “the belief that some health issues are beyond human control, encompassing notions of luck, fate, and predestination” (Straughan & Seow, 1998, p. 88). Constructs related to fatalism in the literature include a lack of control over external events in one’s life; concepts of fate, luck, and predestination (Davison, Frankel, & Smith 1992; Straughan, & Seow, 1998); and feelings of powerlessness, hopelessness, and meaninglessness (Powe & Johnson, 1995).

Theoretical Perspectives on Fatalism

People's perceptions of control over their own health status, are believed to be major determinants of their health-related behavior and long term health outcomes (Wallston, 1992). According to Rotter (1990), locus of control orientation refers to the degree to which one believes that an outcome is contingent upon one’s actions as opposed to chance, luck, or fate or the actions of powerful others. When health status is interpreted as being beyond one’s personal control, one has an external locus of control orientation and tends to be more fatalistic. An individual who perceives that health status is contingent upon personal behavior or characteristics is displaying an internal locus of control orientation (Rotter, 1975). Misconceptions of Rotter’s locus of control construct resulted in a dichotomy, in which persons were categorized as either “correct” and complying with “good lifestyle choices” (internals) or

externals/fatalists who were viewed as ignorant, irrational, and in need of some sort of intervention, such as education (Davison et al., 1992).

Freeman's poverty-cancer spiral viewed cancer fatalism as an interrelationship between race, poverty, and cancer (Freeman, 1989). The financial burden of cancer itself can be impoverishing, and Freeman identified poverty as a prism from which cancer fatalism emerges. The poor tend to focus on day-to-day survival rather than preventive health care; therefore cancer is more likely to be diagnosed in advanced stages, with poor prognosis and probable fatality. Over time, people come to believe that there is no way out of this cycle of cancer and death (Freeman, 1989). In this perspective, cancer fatalism emerges from an individual's perceptions that cancer is inevitable regardless of the person's actions and that screening will not prevent cancer from occurring or affect the outcome.

Freeman's work focused on the direct and indirect influences of poverty on fatalism and cancer screening among the poor. Powe & Johnson (1995) disagreed that cancer fatalism among African-Americans emerged from poverty alone and suggested that cancer fatalism derives from the cultural, historical, and socio-economic factors that contribute to experiences of oppression and perceptions of meaninglessness, hopelessness, and social despair (Powe & Johnson, 1995).

Because cancer fatalism encompasses perceptions of powerlessness and hopelessness (Powe, 1996), individuals with fatalistic attitudes may perceive that they have no control over their health, which, in turn, influences decisions about health promoting behaviors. This perspective led to the development of the Powe Fatalism Model (PFM) (Powe, 1995), one of the first conceptual frameworks used to examine relationships among demographic factors, fatalism, knowledge of cancer, and participation in cancer screening.

The PFM expands on Pender's behavior-specific cognitions and affect category, which includes perceived benefits and barriers to behavior, perceived self-efficacy, and cues to behavior (Powe, 1997). Pender (1987) theorized that positive cognitive-perceptual factors serve as motivators for health promoting behavior; therefore, perceptions of personal control should result in increased health promoting behavior. From Pender's perspective, one can assume that an individual who perceives that he or she has no control over their health will also perceive a lack of benefit to health promoting behavior and lack of self-efficacy in executing such behaviors.

Numerous studies examining cancer fatalism and screening have adopted the Health Belief Model (HBM) (D'Agostino, Farmer, Jackson, & Reddick, 2007; Smith-Howell et al., 2011). Principle variables identified in the HBM include the perceived value of a health goal and the likelihood that action will accomplish that goal. The HBM postulates that people will take action to prevent, to screen for, or to control conditions of ill health if they (a) regard themselves as susceptible to the condition, (b) believe it could have potentially serious consequences, (c) believe that a course of action available to them would be beneficial in reducing either their susceptibility to or the severity of the condition, and (d) believe that the anticipated barriers to (or costs of) taking the action are outweighed by its benefits (Champion, Janz, & Stretcher, 2002).

Straughan and Seow (1998) argued that "rationality itself is based on cultural and social norms" (p. 86) and criticized the HBM as culturally inappropriate for various ethnic groups because it is based on the assumption that adherence to Western biomedical claims is rational. Straughan and Seow's work on cancer fatalism is built on the assumption that fatalism influences self-efficacy, which in turn affects acceptability of cancer screening tests. Bandura's (1994) social cognitive theory is based on the assumption that self-efficacy affects self-directed change and maintenance of health promotion behavior such as cancer screening participation, therefore

Straughan and Seow argued that adopting this theory would be more appropriate for understanding and changing health behavior.

Different theoretical frameworks and various conceptual perspectives related to its origins have resulted in several limitations of fatalism studies. These limitations include misinterpretations of fatalism constructs across different populations and poor validity of fatalism measures.

Cultural Foundations of Fatalism

Culture fundamentally shapes how individuals make meaning of illness, suffering, and dying (Clements, Vigil, Manno, Henry, & Wilks, 2003; Gany, Herrera, Avallone, & Changrani, 2006). Several studies have shown that culturally related health practices and beliefs, such as fatalism, have a significant influence on cancer screening behaviors (Kagawa-Singer, Valdez, Yu, & Surbone, 2010; Kwok & Sullivan, 2006).

Fatalistic beliefs have been found to integrate cultural values worldwide (Davison et al, 1992; Powe & Johnson, 1995; Straughan & Seow 1998; Florez et al., 2009; Keeley et al., 2009; Drew & Schoenberg, 2011). Variations in how fatalistic beliefs are expressed and differences in levels of fatalistic orientation vary from culture to culture. One explanation for these differences may be related to the differences in religious backgrounds among different cultural groups, since religious beliefs have been known to influence perceptions of fatalism (Kwok & Sullivan, 2006).

Kwok and Sullivan (2006), for example, found that Chinese-Australian women's beliefs about life, aging, sickness, and death were viewed through the lens of Buddhism, Taoism, and Confucianism, which comprise a significant part of their upbringing and daily lives. Developing a disease such as cancer was associated with the natural lifecycle in the Chinese philosophy of birth, aging, sickness, and death. Not only did Chinese women perceive death and illness as part

of the natural lifecycle, which cannot be altered, but they also believed that its timing was preordained and any attempt to alter it was useless (Kwok & Sullivan). Attachment of social and cultural meanings to occurrences of health and illness according to the Chinese lifecycle philosophy legitimizes fatalistic attitudes that are protected under its cultural and religious beliefs. Therefore, Chinese women who are fatalistic are behaving rationally when they avoid participation in screening tests because, in their own cultural worldview, screening is not beneficial in decreasing their risk of getting cancer or dying from it (Seow, Huang, & Straughan, 2000).

Powe (1996) suggested that conceptual ambiguity surrounding cancer fatalism among various oppressed minority groups derives from historical lived experiences and cultural beliefs. Powe and Johnson (1995) contended that fatalism represents the surrender of the human spirit to external forces that destroy human personality, potential, hope, and life. Among African Americans, for example, oppressive forces such as slavery, segregation, discrimination, substandard healthcare, and subsequent perceptions of meaninglessness, hopelessness, and social despair, provide the environment for the emergence of cancer fatalism (Powe, 1996). In the historical context of racism and discrimination, fatalism represents a denial of the possibility of hope in life and a concomitant resignation to death (Powe & Johnson).

Davison et al. (1992) argued that people seldom embrace an entirely internal or external belief in determinants of health, and fatalistic attitudes are not an alternative to a lifestyle-oriented viewpoint but rather emerge from an individual's personal experience within their environment. Fatalism has been found to be a culturally acceptable coping attitude when enduring adverse conditions, such as poverty. It is believed that fatalism in underserved

populations may have emerged as a realistic adaptation to the limitations imposed by external realities.

Drew & Schoenberg's work (2011) with Appalachian women in Kentucky revealed that although Appalachian women expressed fatalistic attitudes about seeking healthcare, such attitudes did not necessarily signify powerlessness or hopelessness but rather a culturally acceptable way of coping with challenging circumstances that derive from social and economic constraints. Appalachia is a distinct geographic area of the United States with its own cultural identity. Fatalism is a notable characteristic of Appalachian culture and manifests itself in a tendency to focus on a present, living-day-to-day orientation and giving little thought to the future (Bauer & College, 2003; Phillips, 2007). According to Drew & Schoenberg (2011), minority groups found to have higher fatalistic attitudes are often perceived as behaving irrationally, when they may be exhibiting appropriate responses to circumstances.

Measuring Cancer Fatalism

Several scales have been developed to measure cancer fatalism (Abraido-Lanza et al., 2007; Powe & Finnie, 2003). Criticisms of studies that have adopted these scales have questioned their lack of reliability and validity partly because (a) the meaning of items in these scales may differ across diverse cultures, and (b) fatalistic ideas may vary across populations. Therefore, standard instruments may not be applicable across different cultural groups (Abraido-Lanza et al.).

One of the most widely used instruments to measure cancer fatalism is the Powe Fatalism Inventory (PFI). Although the PFI has demonstrated good reliability, its limited content validity and lack of evidence for construct validity have been criticized (Shen, Condit, & Wright, 2009). The scale was originally developed and tested on African-Americans based on conceptions of

fear, predetermination, pessimism, and inevitable death associated with cancer (Powe, 1995).

Studies of cancer fatalism that utilized the PFI in Chinese and Hispanic groups have reported poor reliabilities (Abraido-Lanza et al., 2007), partly due to differences in conceptions of fatalism among various cultures (Shen et al., 2009).

Studies on Cancer Fatalism

Although fatalism has been suggested as an independent predictor for cancer screening participation in diverse ethnic populations (Baron-Epel, Friedman, & Lernau, 2009), differing ambiguous conceptions of its meaning, definition, and measurement have led to premature assumptions concerning the health ramifications of fatalistic beliefs (Abraido-Lanza et al., 2007). For example, Powe & Johnson (1995) identified powerlessness and hopelessness as contextual factors that give rise to fatalistic cancer-related beliefs among African Americans. However, in a qualitative study conducted by Florez et al. (2009) to explore views and beliefs about cancer fatalism in Dominican Hispanic women, the authors concluded that complex strategies and beliefs regarding breast cancer and cancer screening among Dominican women derived from a perspective of resiliency rather than hopelessness.

Earlier studies of cancer fatalism among African Americans implied that cancer fatalism was an independent variable responsible for decreased participation in cancer screening, operating independently of other variables such as education and poverty (Powe, 1996). Powe pointed out that even when issues of poverty, poor access to health care, lack of knowledge, and decreased education are statistically controlled, African Americans have more fatalistic attitudes about cancer screening than whites. Powe also reported a strong relationship between high fatalism scores and decreased participation in cancer screening. In one of the first theory-based studies to examine the relationship between cancer fatalism and social demographic factors,

fatalism was a significant predictor of colorectal cancer screening among elderly African American women (Powe, 1995). Despite the fact that participants received free transportation to the screening site, a free educational program on cancer screening, and no-cost colorectal cancer screening, elderly African American women did not participate in screening. When demographic factors, such as age, education, and income, were statistically controlled, fatalism was the only significant predictor of colorectal cancer screening participation (Powe, 1995).

Mayo, Ureda, & Parker (2001) examined the influence of fatalistic beliefs in breast cancer screening participation among African American women and found that fatalism was associated with decreased mammography participation in univariate analysis, but after adjusting for possible confounding variables (age, education, and physician recommendation), fatalism was not significantly associated with decreased participation. Similarly, although Latinos may verbalize fatalistic perceptions that little can be done to change their fate, some studies have found that, after controlling for potential confounders such as education, poverty, and access to healthcare, fatalism was not significantly related to cancer screening in this population (Abraido-Lanza et al., 2007).

Straughan and Seow (1995; 1998) studied fatalism among women of Chinese descent, and conducted one of the first studies to examine the relationship between self-efficacy and fatalism. They reported that Chinese women were very fatalistic, had low self-efficacy, and did not accept cancer screening tests based on their cultural beliefs. Because fatalism derived from cultural and religious beliefs rooted in the Chinese philosophical lifecycle where illness and death are inevitable, it was suggested that the notion of fatalism itself was a cause of low self-efficacy (Straughan & Seow, 1998). In their qualitative interviews with Chinese women, Straughan and Seow found that avoiding talking about it or tempting fate was one method of

preventing breast cancer . The taboo against discussing cancer among Chinese women was also noted in study by Gany et al. (2006). Not participating in cancer screening is a rational response to their belief in the repercussions of tempting fate by obtaining screening.

These findings were replicated in a more recent study of the acceptance of Pap smear screening among Chinese women living in Singapore. Seow et al. (2000) found that among women who were aware of the Pap smear and its benefits in early cancer detection, acceptance of the test was related to both social and cultural factors.

Kwok & Sullivan's (2006) study of Chinese-Australian women showed that cancer screening tests were culturally unacceptable in disease prevention because most of the women viewed illness and disease as something associated with aging and the natural cycle of life. These beliefs were derived from their Buddhist faith which views aging, illness, and death as a natural process. For these women, not participating in cancer screening was a rational behavior because developing illnesses, such as cancer, is preordained; therefore, detecting cancer would not change the outcome.

Although most of the women associated cancer with death, misery, catastrophe, pain, suffering, fear, and hopelessness, the concept of fatalism in Chinese culture did not denote passivity. Cultural norms for illness prevention included engaging in what Western society identifies as health promotion, including tobacco cessation, regular exercise, healthy diet, and abstaining from excessive alcohol consumption. In Chinese culture, it is not acceptable to alter what is preordained by destiny, such as illness. However, an individual is not helpless and is expected to take all precautions that will delay illness by engaging in health promoting behaviors. Chinese women's concept of health promotion included strengthening the body's resistance to disease by engaging in health promoting behaviors. Several of the women also perceived

speaking about cancer as taboo, and not thinking about cancer was seen as a way to prevent it (Kwok & Sullivan).

Drew & Schoenberg's (2011) interviews with Appalachian women suggested that lack of awareness of Pap smear tests was rare, but women avoided screening due to their constrained realities, including fear of finding cancer and not being able to obtain medical treatment if cancer was detected. Health care in Appalachian Kentucky is marked by physician shortage, lack of specialists, and barriers to access due to greater distances to clinics and hospitals, which may be as much as 200 miles (Bauer & College, 2003). Many Appalachians would be reluctant to relocate for treatment because of a deep commitment to their extended families and their culture.

Roncancio, Ward, & Berenson (2011) found that Hispanic women with more fatalistic attitudes were more likely to believe that health care providers control their health than those with less fatalistic attitudes. In addition, women who were less acculturated were more likely than highly acculturated women to believe that health care providers control their health, leading to the conclusion that health care providers have the ability to improve their patients' adherence to screening guidelines and treatment even when highly fatalistic attitudes are acknowledged.

Implications for Practice and Research

Previous research has assumed that fatalism is a global, stable belief, measureable by survey instruments that are abstracted from specific contexts (Keeley et al., 2009). This research stream has resulted in a fatalism complex which perceives a negative association between fatalism and demographic factors such as education, income, and socioeconomic status (Davison et al., 1992; Drew & Schoenberg, 2011; Straughan & Seow, 1998). Studies have documented that socioeconomic status alone does not account for cancer disparities among minority groups and cultural beliefs can play a significant role in early cancer detection and prevention (Powe, 1995).

Fatalism is one of these cultural beliefs and has been shown to be a significant barrier to cancer screening among ethnic minorities and underserved populations (Powe, 1995; Drew & Schoenberg, 2011).

Communication barriers between patients and providers can hinder early detection and treatment and influence decision making (Kearney, Miller, Paul, Smith, & Rice, 2003). The most highly ranked predictor of cancer screening participation is receiving a recommendation from a health care provider (Breen, Graubard, Meissner, Taubman, & Vernon, 2007; Davis, Marcantonio, McCarthy, Schonberg, & York, 2007). Healthcare providers may perceive patients as fatalistic, when in reality patients' perceptions of cancer fatalism may be significantly lower than what their health care providers may believe them to be (Powe, Daniels, & Finnie, 2005). Misinterpretations of health values and behaviors are likely to occur when members of different subcultures interact, such as in a patient-provider interaction during a medical visit. These same misperceptions of patient fatalistic attitudes by health care providers may ultimately influence provider recommendation for early cancer detection screening.

The influence of providers' cultural proficiency on cancer outcomes highlights the importance of developing effective cancer prevention services for diverse populations. Culture influences the meanings associated with cancer, yet culture is still poorly understood and infrequently applied in clinical settings serving diverse communities (Kagawa-Singer et al., 2010). In an effort to develop culturally sensitive health care services, program planning must incorporate knowledge of the target populations' cultural beliefs about health and illness (Davison et al., 1992; Kwok & Sullivan, 2006).

Lack of consistent conceptual frameworks to evaluate and interpret cancer fatalism has resulted in limited development of effective strategies to eliminate cancer disparities among

minorities. Future research in cancer fatalism is needed to clarify theoretical frameworks and constructs and to improve the validity of fatalism measures, analysis, and interpretation. Once factors contributing to fatalism have been identified, interventions to diminish fatalism can be tested.

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Knowledge, Fatalism, and Mammography Screening in Older Women

Abstract

Objective: The purposes of this study were to (a) examine perceptions of cancer fatalism among older women who attend senior nutrition programs in underserved areas of San Diego County, (b) examine older women's knowledge of breast cancer and participation in mammography screening, and (c) identify relationships among levels of knowledge, fatalistic attitudes, and mammography participation.

Design: A quantitative descriptive correlational study.

Sample: A non-randomized, volunteer sample of 47 women 65 years of age and older who attend nutrition programs at senior community centers in San Diego County.

Measurements: Data were collected using the revised Powe Fatalism Inventory, Breast Cancer Knowledge Questionnaire, and a demographic questionnaire.

Results: Significant associations were noted among age, knowledge, and fatalism.

Conclusion: The number of older women who do not obtain mammography screening based on current recommendations has not changed over the last decade. Lack of knowledge continues to be a significant barrier in screening among older women. Appropriate interventions are needed to address cancer morbidity in this underserved population group.

Keywords: breast health, mammography, older women, fatalism, knowledge

Knowledge, Fatalism, and Mammography Screening in Older Women

Background

Age is the most common risk factor for breast cancer (American Cancer Society [ACS], 2009).

Nearly half of breast cancer diagnoses and more than half of deaths occur in women over the age of 65 (American Geriatrics Society [AGS], 2005). Mammography is the best available screening tool for breast cancer detection (Susan G. Komen Foundation, 2008), and early stage at the time of diagnosis is an important predictor of survival. Approximately 81% of breast cancers detected in older women are hormone dependent tumors, for which hormone treatment can be successful if initiated early (Paraskakis & Petrakis, 2010).

Breast Cancer Incidence and Screening Disparities

According to the United States Preventive Services Task Force (USPTF, 2009), women 60 to 69 years of age receive the greatest benefit of early breast cancer detection; early detection by mammography screening in women 75 to 84 years of age is also associated with reduced mortality (Galit, Green, & Lital, 2007). Although older women bear the highest breast cancer risk and highest mortality (ACS, 2009; Surveillance Epidemiology and End Results [SEER], 2009), they are less likely than younger women to participate in mammography screening. The 2005 National Health Interview Survey findings indicated mammography screening is poorly utilized among women over 65 years of age (Leveille, Marcantonio, & Schonberg, 2008). Older women diagnosed with breast cancer often present with larger tumor size and later stage, are more likely to have metastatic disease at the time of diagnosis, and are less likely to have had a mammogram in the prior two years than younger women (Brown, Garg, Kumarl, Reed, & Wyld, 2004).

Age-related breast cancer screening disparities and advanced disease at the time of diagnosis are contributing factors in increased mortality in older women (Brown et al., 2004). Older women of lower socioeconomic status have been noted to be at greater risk for not receiving mammography screening and breast cancer mortality than other women (Casella et al., 2010; Williams, Lindquist, Sudore, Covinsky, & Walter, 2008). The literature identifies healthcare provider recommendation, breast cancer knowledge (including perceived benefits of mammography participation and perceived risk of breast cancer), and cancer fatalism as potentially modifiable factors relevant to older women's decisions about mammography screening participation (Brooks, Hamilton, & Powe, 2006; Linsell, Burgess, & Ramirez, 2008).

Healthcare Provider Recommendation

Healthcare provider recommendation has consistently been acknowledged as the most important factor older women consider when making decisions about mammography participation. Approximately 80% of women without a mammogram in the previous 2 years reported not obtaining a mammogram because their physicians had not recommended one (Breen, Graubard, Meissner, Taubman, & Vernon, 2007; Davis, Marcantonio, McCarthy, Schonberg, & York, 2007).

Davis et al. (2007) found that a physician's recommendation was one of the most highly ranked factors influencing mammography screening decisions. In their study, women over 80 years of age who chose not to obtain a mammogram ranked age and then physician's recommendation as the most important factors influencing their decision. The study stressed the importance of healthcare providers counseling older women on mammography screening, particularly explaining that health, rather than age, should be considered when making decisions.

Breast Cancer Knowledge

Older women's knowledge of breast cancer risks and symptoms is often lower than that of younger women, and they are less likely to seek medical attention promptly for a breast change. Linsell et al. (2008), in a study to assess knowledge of risks and symptoms of breast cancer in older women, found that the main knowledge deficits were lack of recognition of symptoms other than a breast lump and poor understanding of risk. In their study, approximately 75% of respondents were not aware that age was a risk factor. This finding was noted even among the most educated group of women, who appeared more likely to believe that older age decreases the likelihood of developing breast cancer.

Interviews with older women conducted by Collins et al. (2010) demonstrated that most women who did not participate in mammography screening assumed they were no longer at risk for breast cancer because they had not received an invitation to participate from their providers. Furthermore, women expressed a desire for more information about the risks and benefits of breast cancer screening in their age group to feel competent in making informed decisions about mammography.

Cancer Fatalism

Psychosocial and cultural beliefs about breast cancer screening have been identified as important determinants of older women's participation in mammography screening. Cancer fatalism, or the belief that cancer is predetermined and death is inevitable when cancer is present, is one such cultural belief (Finnie & Powe, 2003). Women who believe that breast cancer develops due to fate are less likely to participate in mammography screening because they do not believe that early cancer detection will change a preordained outcome, such as breast cancer (Kwok & Sullivan, 2006).

Research has suggested that perceptions of cancer fatalism are most evident among women, older persons, persons with lower levels of education, those with decreased income, and members of racial and ethnic minority groups, and that these perceptions influence decisions to participate in cancer screening (Brooks et al., 2006). Mayo, Parker, and Ureda (2001) identified age, race, and education as demographic predictors of fatalism and supported fatalism as a significant correlate of mammography participation among elderly women. In elderly women of diverse ethnic populations, cancer fatalism has been suggested as an independent predictor of participation in cancer screening (Baron-Epel, Friedman, & Lernau, 2009).

There is limited research addressing barriers to older women's mammography participation and their perceptions (including fatalistic beliefs) of mammography screening. Findings from Brooks et al (2006) indicated that breast cancer knowledge and perceptions of cancer fatalism among older women influence decisions to participate in cancer screening. Interventional studies have implied that an increase in breast cancer knowledge may increase mammography participation among older women (Burgess et al., 2009) by reducing cancer-related fatalism, but the consistency of this link has not been demonstrated. The present study addresses identified barriers to mammography screening in underserved older women, including breast cancer knowledge and fatalistic beliefs.

Research Objectives

The primary study objectives were to describe older women's knowledge and perceptions of breast cancer, mammography participation, and fatalistic attitudes and to identify correlates among variables. Specifically, the study addressed the following research hypotheses:

1. There will be a significant negative correlation between fatalism scores and cancer knowledge scores.

2. There will be a significant negative correlation between fatalism scores and mammography participation.
3. There will be a significant positive correlation between breast cancer knowledge scores and mammography participation.

Conceptual Framework

Beliefs and attitudes affect cancer screening behaviors. The conceptual framework chosen for this study is the Health Belief Model (HBM). The model has been applied in several studies to guide the development of health interventions to change behavior. During the past decade, the HBM has been tested with older African American women and used to explain and predict breast cancer screening behaviors (D'Agostino, Farmer, Jackson, & Reddick, 2007).

The HBM has six fundamental constructs: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy. The HBM postulates that people will take action to prevent, to screen for, or to control conditions of ill health if they regard themselves as susceptible to a condition, if they believe it could have potentially serious consequences, if they believe that a course of action available to them would be beneficial in reducing susceptibility to or the severity of the condition, and if they believe that the anticipated barriers to (or costs of) taking the action are outweighed by its benefits (Champion et al., 2003).

The primary HBM variables addressed in this study were as follows:

Perceived susceptibility and severity. Many women understand that mammography successfully detects breast cancer, but do not see themselves at risk if they are asymptomatic or have no family history of the disease (Ahmad, Austin, McNally, & Stewart, 2002). Perceptions of “cancer as a death sentence” reported by some minority group members and older people are

an example of the perceived severity of the disease. A combination of perceived susceptibility and severity creates a perceived threat of illness

Perceived benefits. The model concepts of perceived benefits and self-efficacy relate to fatalistic attitudes among some women. Many older women and women of ethnic minority groups perceive cancer screening as not beneficial based on beliefs that they will either develop cancer or not and that the outcome is beyond their control. This attitude stems from a fatalistic belief that there is little one can do to alter fate or prevent cancer, leading to a sense of powerlessness, which may account for some of the anxiety associated with cancer (Ahmad et al., 2002).

Perceived barriers. Many women perceive a variety of barriers to mammography screening. For example, among Thai American women, family and employment responsibilities were identified as barriers to screening, as was reluctance to display one's breasts. Other logistic barriers to screening included cost, transportation, and language barriers (Clark & Natipagon-Shah, 2008).

These HBM variables were used to examine older women's perceptions of risk, benefits, and barriers to mammography participation by measuring levels of knowledge and levels of fatalism. Because all of these factors have been linked with mammography screening (Champion et al., 2003), it was hypothesized that there would be a significant negative correlation between fatalism scores and mammography participation, and a significant positive correlation between breast cancer knowledge scores and mammography participation. The conceptual framework for the study is depicted in figure 1.

Methods

Design

A quantitative, descriptive correlational design was chosen for this study. Study participants included a non-randomized, volunteer sample of 47 women 65 years of age and older who attended senior nutrition programs at community centers in underserved areas of San Diego County.

Eligibility criteria. Women over 65 years of age, who attended senior lunch programs at community centers located in underserved areas of San Diego County were invited to participate. Participants included women with or without personal or family history of breast cancer who were able to speak and read English.

Sample recruitment and protection of human subjects. Power analysis computations based on a 0.05 level of significance, a medium effect size (alpha 0.05), and an estimated power of .95 (95%) yielded a required sample size of 43. After obtaining permission from the community center senior programs coordinators and IRB approval from the University of San Diego, the primary investigator (PI) scheduled sessions to meet with potential participants during regular lunch program hours. In addition, flyers were posted in the dining halls one week prior to each scheduled session. The PI explained the research project and its voluntary nature during scheduled lunch session to groups of older women eligible to participate in the study. Women who expressed interest in participating received written and verbal information about the study's purpose, the voluntary nature of participation, the ability to discontinue participation at any time, confidentiality of the data, and potential risks and benefits of participation prior to agreeing to participate. The PI reviewed the informed consent form with prospective participants and obtained written consent. Participants received five dollar gift cards to a local grocery store.

Setting

The study was conducted at four community centers offering senior lunch programs in underserved areas of San Diego County. The senior lunch programs were selected as an appropriate setting for recruiting participants because women who meet the eligibility criteria would be accessible and because the programs serve low-income elderly individuals from diverse ethnic and racial groups. The four different sites facilitated a larger population sample, representing older women from different underserved areas of San Diego County.

Two sites served lunch once a day Monday through Friday; 2 sessions were scheduled at each of these sites. One site delivered meals primarily to homebound seniors and only one session was scheduled at this facility. The fourth site served lunch at 3 different times daily Monday through Friday and once daily on Saturday and Sunday. Four sessions were scheduled at this facility to accommodate seniors interested in participating. A total of nine sessions were conducted.

Measures

Data were collected using a demographic questionnaire, Breast Cancer Knowledge Questionnaire, and the revised Powe Fatalism Inventory.

Demographic data questionnaire. A demographic questionnaire developed by the PI was used to obtain information regarding participants' age, income, medical insurance coverage, education level, and personal or family history of cancer. The last question on the demographic form elicited information about the participant's last mammogram.

Breast Cancer Knowledge Questionnaire. Breast cancer knowledge was measured using the 15-item Breast Cancer Knowledge Questionnaire from the Breast Health Intervention Evaluation Study (BRIES). BRIES was a federally funded intervention study to

evaluate the effectiveness of three different approaches (a fear approach, a positive approach, and a neutral, cognitive approach) to breast health messages among African-American women living in three rural communities in Georgia. The questionnaire was reviewed by experienced survey and community-based research faculty members to establish its validity. The questionnaire was also pre-tested to determine suitability with the target population of the BRIE study (Blumenthal, 2001). The tool was used most recently with African American adult daughters of mothers with breast cancer to measure breast health and breast cancer knowledge (Callahan, 2008).

Items on the questionnaire focus on breast health knowledge, including awareness of breast cancer warning signs and attitudes toward breast cancer. The questionnaire is divided into 3 sections. The first section addresses awareness of breast cancer warning signs. The question “What do you think are the warning signs of breast cancer?” is followed by a list of 10 possible responses, 8 of which are correct and 2 incorrect. Participants were asked to mark each correct item and were given one point for each correct answer for a total of 10 points (8 points for identifying the 8 correct warning signs, and 2 points for not marking the 2 incorrect responses). Higher scores indicate higher levels of knowledge. The second section addresses knowledge of breast cancer and breast cancer screening and includes five true/false questions. Each correct answer was given a point for a maximum of 5 possible points; higher scores indicate higher levels of knowledge. Because the questionnaire has not been used in an exploratory analysis, a Cronbach’s alpha was calculated, yielding Cronbach’s alphas of 0.653 for section 1 and 0.475 for section 2. The third section measures attitudes about breast cancer and includes Likert-type scale questions. For this section, descriptive analysis was conducted and responses to each

question were analyzed item by item, consistent with past use of the questionnaire (Blumenthal, 2001; Callahan, 2008).

Revised Powe Fatalism Inventory (rPFI). Fatalism, in this study, was defined as the belief that breast cancer is inevitable, and regardless of what is done, leads to death. Fatalism was measured using the rPFI developed by Mayo, Parker, and Ureda (2001). The rPFI consists of 11 items specific to breast cancer and was developed through a multi-stage process of qualitative interviews, factor analysis, and multiple revisions. The authors selected the items on the rPFI based on the defining beliefs demonstrated by individuals with strong beliefs in cancer fatalism, which include fear, predetermination, pessimism, and inevitability (including ideas of “God’s will”). The rPFI scales measure the defining characteristics of fatalism related to breast cancer (items 1-3), breast cancer screening (item 4), and the course of cancer and death (items 5-11). There is one item specific to the belief that breast cancer is God’s will.

Response options for each question are yes (scored as one point), or no (scored as zero points). The maximum score is 11 points, and higher scores indicate stronger beliefs in cancer fatalism. The rPFI was pilot tested by the developers on a group of 60 elderly women to establish its reliability and validity, and was found to have a Cronbach’s alpha of 0.89 during pilot testing. Factor analysis, using principal component analysis, resulted in all items in the scale loading on only one factor with factor loadings of 0.40 or greater (Mayo et al., 2001). The instrument’s Cronbach’s alpha in the current study was 0.873

Data collection and Analysis. Data collection occurred over 6 months from February 17, 2011 to September 13, 2011. Following the usual lunch at the senior center, participants completed the three questionnaires, which took approximately 60 minutes. Completed questionnaires were reviewed, scored, and entered into a computer database using assigned code

numbers. Quantitative data were analyzed using SPSS software. Descriptive statistics consisted of measures of central tendency (e.g., mean, standard deviation, minimum, maximum, frequency distributions) relating to the demographic characteristics of the sample population and study variables. Hypotheses were tested using Spearman's rank correlation coefficient, which examines relationships among variables measured on an ordinal scale.

Results

Descriptive Findings. Frequency and percent distribution by age, race, income, healthcare insurance status, education, personal and family history of breast cancer, and previous mammography participation are presented in Table 1. All the participants in this study resided in San Diego County and participated in free or donation-fee lunch programs provided by senior community centers located in underserved areas of San Diego County. Ages ranged from 65 to 80 + years, and 64% were in the 65 to 74 age group. The ethnic/racial distribution of the population is depicted in Table 1 and underrepresents the Hispanic population of the county. Nearly two thirds of the women reported annual incomes less than \$15,000. Most participants were high school graduates (34%) or had some college or technical school education (31.9%). Over 80% of the women were Medicare recipients, but nearly 9% had no health insurance coverage. Almost half of the women (45.5%) had a family history of breast cancer, and four women had a previous history of breast cancer themselves.

Mammography participation. Approximately two thirds (65%) of the women had had a mammogram within the last two years, but 35% of the respondents were outside the parameters of mammography frequency, having had their last mammograms more than two years ago. Two of those women reported never having a mammogram. These figures do not meet the Healthy

People 2020 mammography screening target of 81.1% for women based on the most recent guideline recommendations (Healthy People, 2012).

Knowledge. Knowledge was measured using sections 1 and 2 of the BRIES questionnaire as described above. The mean scores and standard deviations for knowledge are presented in Table 2. There was a significant negative correlation between age and knowledge ($r = -0.372$, $p = 0.012$). The majority of the women were aware of common breast cancer symptoms related to changes in their breasts (a new lump, pain, fluid leaking). Only 55% reported swelling or enlargement of the breast and 60% changes in the color of the skin on the breast as potential signs of breast cancer. Most women (70%) believed that mammograms were effective at detecting breast cancer, and 85% believed that breast cancer could be cured if detected early. Consistent with the findings from previous studies, most women (53%) were not aware that getting older increases a woman's chance of getting breast cancer.

In evaluating the women's attitudes about breast cancer, 73% of the women strongly agreed that mammograms are worth it and that they were responsible for taking care of their own bodies, including their breasts (88%).

Fear and embarrassment have been reported as barriers to mammography participation in previous research, but only 20% of the women reported not wanting to get a mammogram because they were afraid of what it might show. In fact, more than half of the women (54%) strongly agreed that they were not afraid of getting a mammogram. Women mostly or strongly disagreed that obtaining a mammogram was embarrassing (76%), and nearly half (46%) agreed that mammograms can hurt.

In response to the question "Breast cancer is the will of the Lord", 68% strongly disagreed. This was consistent with Callahan's (2008) findings among African American

mothers diagnosed with breast cancer and their daughters, in which 69% mostly or strongly disagreed that breast cancer is the will of the lord.

Previous studies have associated increased levels of knowledge with decreased levels of fatalism (Powe & Weinrich, 1999). Although this study did not support a significant relationship between fatalism and levels of knowledge, there was a significant negative correlation between level of education and fatalism ($r = -0.337$, $p = 0.020$).

Fatalism. A summary of the women's responses to the rPFI questionnaire reflecting fatalistic beliefs is presented in Table 3 as frequency and percent distributions. In previous studies, a score greater than 5 on the rPFI was indicative of a high level of fatalism (Mayo et al., 2001). The mean score for the women in this study was 2.2, indicating low levels of fatalism. Mean fatalism scores by age and race are depicted in Figure 2.

In evaluating women's beliefs about breast cancer, 76% did not believe that breast cancer is part of God's plan. Item 4 elicited the defining characteristics of fatalism related to breast cancer screening by asking the question "I believe if someone has breast cancer, it is already too late to do anything about it," and 89% of women answered "no" to this question.

Relationships Among Variables. Findings related to relationships addressed in each of the three study hypotheses are presented below. In addition, relationships of study variables to demographic characteristics are explored.

Hypothesis 1 addressed the relationship between fatalism scores and cancer knowledge scores for sections 1 and 2 of the BRIES questionnaire. A Spearman's rank correlation coefficient was used. Although there was a trend toward negative relationships of scores on section 1 and section 2 of the BRIES with fatalism scores, the correlations did not reach statistical significance ($r = -0.272$, $p = 0.064$ and $r = -0.257$, $p = 0.081$, respectively).

Hypothesis 2 addressed the relationship between fatalism scores and mammography participation. Participants were asked “when was your last mammography?” To trend the data in the direction that we hypothesized, greater scores indicated greater time since the last mammogram for a score ranging from 1 to 4 (with 4 being “never had a mammogram”). Using a Spearman’s correlation, there was a trend toward a negative correlation of fatalism scores with mammography participation, but, again, it was not significant ($r = -0.179$, $p = 0.235$). This may be due to the relatively low fatalism scores found among participants.

Similarly, data related to hypothesis 3 indicated a slight trend toward scores on parts 1 and 2 of the BRIES being positively correlated with mammography participation, but the relationships were not significant ($r = 0.103$, $p = 0.497$ and $r = 0.196$, $p = 0.192$, respectively).

With respect to the influence of demographic characteristics, there was a significant negative correlation between age and knowledge scores on both sections 1 and 2 of the BRIES ($r = -0.372$, $p = 0.012$; $r = -0.316$, $p = 0.035$) and a significant positive correlation between age and fatalism ($r = 0.353$, $p = 0.017$). Similarly, a significant positive relationship was noted between race and mammography participation, with African Americans being more likely (37%) than Caucasians (19%) to have had a mammogram in the past 2 years.

No significant correlations were found between levels of income and mammography participation or fatalism. Unlike the findings of prior studies, there was no significant correlation between medical insurance status and mammography participation, probably because the large majority of participants were Medicare recipients. It was not surprising that there was a significant negative correlation between level of education and fatalism ($r = -0.337$, $p = 0.020$), but, contrary to previous findings, there was no significant correlation between level of education and knowledge.

Discussion

This study examined the relationships of demographic factors, fatalistic perceptions, and knowledge to mammography participation among older women. Race, age, education, income, resource variables (including provider recommendation and health insurance) fatalism, knowledge, and mammography screening were examined.

It is evident from the findings that the number of women who do not adhere to mammography screening recommendations has not decreased over the last decade. In fact, in comparison to Mayo et al.'s (2001) findings, the percentage of women who did not receive mammograms in the last 24 months increased from 30% to 35%. National data from the Centers for Disease Control and Prevention ([CDC], 2009) from 2000 to 2008, indicated a decrease (from 35% to 32%) in women who were outside of compliance with mammography screening, slightly lower than the percentage of women (35%) who were out of compliance in this study.

According to the United States Preventive Services Task Force ([USPTF], 2009), the greatest benefit associated with early breast cancer detection by mammography screening occurs among women 60 to 69 years of age. In this study, 57% of the women who did not comply with screening recommendations fell within this age group. In contrast to previous studies, this study found that the majority of women who had received a mammogram in the previous 24 months were African American, and 46% of the women who were out of compliance with screening recommendations were Caucasian.

Previous studies that have examined relationships between demographic variables and fatalism have reported inconsistent findings. In this study, 90% of the women ages 65 to 69 scored 5 or less on the rPFI, reflecting very low levels of fatalism. The scores increased with

every age group, indicating that, as age increased, levels of fatalism also increased. Similar findings have been noted in previous studies done by Mayo et al. (2001; 2003) on older women.

Fatalism has been shown to be a significant barrier to cancer screening among ethnic minorities and underserved populations (Powe, 1995; Drew & Schoenberg, 2011). In this study, the relationship between fatalism and mammography participation was not found to be significant, possibly due to limited variability in fatalism scores.

Several studies have reported higher levels of fatalism among ethnic minorities and immigrants (Kwok & Sullivan, 2006; Finnie & Powe, 2003). Consistent with these previous findings, Asians and older age groups in this study exhibited the highest fatalism scores.

With respect to provider recommendation influencing older women's decisions about obtaining a mammogram, the study supported previous research findings. A majority of the women who were not in compliance with mammogram screening recommendations strongly agreed that they would be more likely to obtain a mammogram if recommended by their doctor (71%) or if encouraged by someone close to them such as a spouse or best friend (57%). The findings support the importance of provider recommendation, and those of others in women's decisions about mammography. Based on Spearman's rank correlation, however, there was no significant correlation between mammography participation and physician recommendation.

Study limitations. The study has several limitations. First, due to the small convenience sample, generalizations of study results would not be valid. Second, because data were obtained by self-report, there is potential for bias. Third, variations in how fatalistic beliefs are expressed and differences in levels of fatalistic orientation vary from culture to culture. This could be related to variances in cultural and religious values that have been linked to fatalistic attitudes towards cancer (Kwok & Sullivan, 2006). Due to the cultural variance among the study

participants, there is a strong possibility that the fatalism instrument may not have been culturally appropriate and questions could have been misinterpreted by the women.

Recommendations for future research and implications for public health nursing.

This study supported several factors that the literature review associates with breast cancer disparities among older women. First, decreased mammography screening in older women continues to be an issue in this population. The study indicated that women in the 65 to 69 age group, shown to benefit the most from early breast cancer detection, are those least likely among older women to obtain mammograms. Second, consistent with previous findings, healthcare providers continue to play a key role in addressing decreased mammography participation among older women. More than two thirds of the women who were out of compliance with screening recommendations, strongly agreed that they would be more likely to obtain a mammogram if recommended by their physicians. Third, lack of knowledge continues to be a significant barrier in obtaining mammogram screening among older women. Although most women were knowledgeable of breast cancer warning signs, the majority were not aware that increased age also puts them at risk for the disease. Specifically, the study indicated that women lack knowledge related to breast cancer risks and screening.

Future research studies are needed to develop appropriate interventions to increase awareness of breast cancer risks and screening among older women. Healthcare providers should also be made of aware of their influence on older women's screening decisions. The study did not support a significant correlation between cancer fatalism and mammography participation, this may be due to low fatalism scores. The study found a significant correlation between age and levels of fatalism. The literature review indicates an association between fatalism and seeking medical care. There is a need to further explore fatalism as a potential barrier to

prevention screening. Further examination of fatalism perceptions among elderly women using more culturally relevant scales are needed.

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Table 1
Demographic Characteristics (n = 47)

Characteristic	Frequencies (n)	Percent (%)*
Age		
65-69	20	44
70-74	9	20
75-79	8	18
80+	8	18
Race		
African American	18	40
Caucasian	15	33
Hispanic	2	4
Asian	6	13
Other	4	9
Annual Household Income		
0	1	2
Less than \$10,000	13	30
\$10,000-\$14,999	14	32
\$15,000-\$24,999	4	9
\$35,000-\$49,000	3	7
Unknown	8	18
Healthcare Insurance		
Medicaid	18	38
Medicare	38	80
Tri-Care	4	8
Private	7	14
None	4	8
Education		
Less than high school graduate	5	10
High school graduate	16	34
Some college or technical school	15	31
College graduate	3	6
Advanced college degree	8	17
Have you ever had breast cancer?		
No	42	91
Yes	4	8
Has anyone in your family had breast cancer?		
No	24	54
Yes	20	45
When was your last mammogram?		
Less than 12 months ago	18	39
12-24 months ago	12	26
More than 24 months ago	14	30
Never had a mammogram	2	4

* percentages rounded so may not total to 100%

Table 2

Knowledge and Fatalism Descriptive Statistics (n=47)

Questionnaire	Mean	Std Deviation
BRIE 1	6.85	2.27
BRIE 2	3.3191	1.64
Fatalism	2.21	2.96

BRIE 1 = section 1

BRIE 2 = section 2

Table 3

Revised Powe Fatalism Inventory (rPFI) cancer fatalism item responses (n=47)

Item	No	Yes
I believe if someone gets breast cancer, it was meant to be.	42 (89 %)	5 (11%)
I believe if someone gets breast cancer, it is part of God's plan.	35(76%)	11(24%)
I believe if someone gets breast cancer , it is already too late to do anything about it.	40(87%)	6(13%)
I believe if someone gets breast cancer, it does not matter when they find out about it, they will still die.	41(87%)	6(13%)
I believe if someone was meant to have breast cancer, it does not matter what the doctor tells them to do, they will get breast cancer anyways.	33(70%)	6(13%)
I believe if someone is meant to get breast cancer, they will get it no matter what they do.	32(68%)	15(32%)

Figure 1

Health Belief Model Conceptual Framework

Figure 2
Fatalism score means by age and race

Higher scores indicate higher levels of fatalism

Plan for a Continued Program of Research

Disproportionate breast cancer burdens fall on underserved populations who lack access to screening. In my transition from an extensive clinical nursing background into a novice nurse researcher one of my goals is to continue to build on community program development for early cancer detection and prevention in underserved populations. Long term plans for a breast cancer research career include post doctoral work in community health. Advocating for vulnerable populations will consist of actively participating in community based participatory research partnership programs intended to eliminate cancer disparities in underserved communities.