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The Effects of Culturally Sensitive Education in Driving South Asian Indian Immigrant Women Towards Mammography Screening in New Jersey

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**THE EFFECTS OF CULTURALLY SENSITIVE EDUCATION IN DRIVING
SOUTH ASIAN INDIAN IMMIGRANT WOMEN TOWARDS MAMMOGRAPHY
SCREENING IN NEW JERSEY**

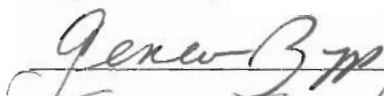
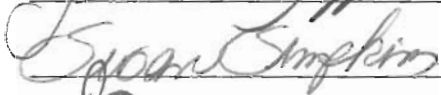
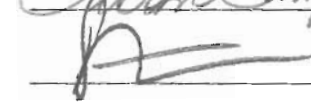
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Submitted in partial fulfillment of the
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Seton Hall University
2010

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Abstract

THE EFFECTS OF CULTURALLY SENSITIVE EDUCATION IN DRIVING SOUTH
ASIAN INDIAN IMMIGRANT WOMEN TOWARDS MAMMOGRAPHY
SCREENING IN NEW JERSEY

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2010

Chair: Dr. Genevieve Pinto Zipp

Background & Purpose of the Study: Breast Cancer is the most commonly diagnosed form of cancer, and is becoming a major public health issue concern for many South Asian Indian immigrant women. However, women of ethnic subgroups and those who immigrated to the United States within the last ten years are less likely to have had a recent mammogram. The purpose of this study is to evaluate a culturally sensitive breast cancer educational intervention on breast cancer knowledge, perception of cancer fatalism, and improved participation in mammography screening among South Asian Indian immigrant women.

Methods: Utilizing a quasi -experimental pretest/post test, follow-up design, the effectiveness of a culturally sensitive breast cancer education intervention on increasing knowledge of breast cancer, decreasing cancer fatalism, and increasing screening intention among a sample of South Asian women was assessed. Data was obtained from 102 South Asian Indian immigrant women who were at least 40 years old. Participants were randomly assigned to a video group (n=51) or brochure group (n=51). Pretest and post-test

intervention, the participants completed several self-administered surveys which assessed cancer knowledge, perception of cancer fatalism, and mammography screening intention.

Results: The results of the 2x2 ANOVA indicate that there was a statistically significant interaction between test and intervention, $F(1, 100) = 62.09, p < .005$, indicating that the relative performance on the two tests differed by intervention group. Participants in the video group had a significant increase ($p = .005$) in the knowledge of breast cancer when compared to the brochure group. However, there was no significant difference between groups on the cancer fatalism scores. After three months post intervention the video group had a 62% participation rate in mammography screening, while the brochure group had a 23% participation rate.

Conclusion: This is the first research study conducted which evaluated the effects of breast cancer education on knowledge of breast cancer among this population. This is also the first study to use a culturally sensitive tool tested on South Asian Indian immigrant women. Culturally sensitive learning experiences increase knowledge and intention to seek mammography screening and thus positively impact overall health management in South Asian Indian immigrant women.

Chapter I

INTRODUCTION

Background of the Problem

Preventing breast cancer is a critical priority in women's health and has led to major public health interventions aimed at increasing the utilization of early detection services (U.S. Department of Health and Human Services, 2003a). Efforts by public health agencies have paid off as evidenced by the reduction of breast cancer mortality rates among Americans, particularly in the Caucasian, middle and upper socio-economic classes (George, 2000; Glanz, Croyle, Chollette, & Pinn, 2003). However, a disparity is seen in the low screening rates among lower socio-economic classes, and non caucasian women. The elimination of health disparities among underserved women is currently a high priority and strategies to reduce the breast cancer burden are urgently needed (Glanz et al., 2003).

Breast cancer is the most commonly diagnosed form of cancer in women (American Cancer Society (ACS), 2008) and the second leading cause of cancer deaths among Asian and Pacific Islander women in the United States. Since the 1980's breast cancer rates have risen 4.5% each year. In 2008, 226,510 women in the United States were diagnosed with breast cancer and an estimated 40,580 women died of breast cancer (ACS, 2008). All women are at risk for breast cancer and the risk increases as women get older, especially after age 40

(ACS, 2008). An advance stage of breast cancer at the time of diagnosis significantly increases mortality rates (ACS, 2008; Hiatt & Pasick, 1996). Thus early detection is imperative.

The focus of cancer screening is on early cancer detection, which generally leads to more positive outcomes, such as increased longevity and quality of life (ACS, 1991; Freeman, 1989). Mammography can detect breast cancer an average of 1.7 years before the lump can be detected manually (Center for Disease Control (CDC), 1998), because mammography can detect cancers that are too small to be detected during a clinical breast examination. Generally, the earlier breast cancer is detected, the better the survival rate (ACS, 1997). When breast cancer is diagnosed after it has spread, the 5-year survival rate decreases to 21% (CDC, 1998). Unfortunately South Asian women (from India, Nepal, Pakistan and Srilanka) have relatively low participation rates in mammography screening services (Islam, Kwon, Senie & Kathuria, 2006).

South Asians represent one fifth of the global population. South Asians are the fastest groups in North America with more than 2 million South Asians reside in the United States and are the fastest growing immigrant group. The South Asian community in New Jersey has experienced the largest growth of any Asian subpopulation, increasing by over 89% to 216,179 individuals in 2000. New Jersey is now home to the largest South Asian population in the United States (US Census Bureau, 2000). Currently, there are no published studies on breast cancer rates among South Asians living in New Jersey. However, studies from India, the

largest country in the South Asian region, have indicated that breast cancer is the most frequently diagnosed malignancy in women (Parkin & Muir, 1992). The majority of research on cancer incidence among South Asian immigrants has been conducted in England (Winter, Cheng, Cummins et al, 1999), where studies have reported higher rates of cancer after migration to the United Kingdom was compared with rates in subjects Country of origin. This pattern is consistent with findings for South Asians living in the United States (Blesch, Davis & Kamath, 1999). Data from the State of California indicates that South Asians experience the third highest 5-year annual age-adjusted breast cancer incidence rate of any Asian American Pacific Islanders (AAPI) subgroup, at 72.9/100,000 women (Kwong, 2004).

National and regional studies of Asian American Pacific Islanders (AAPI) communities have reported low rates of breast cancer screening in general and AAPI subpopulation in particular (Miller, Kolonel & Bernstein, 1996; Sarna, Tae, Kim et al., 2001; Tanjasiri & Sablan, 2001; Kim, Yu, Chen et al., 1998). Studies report low rates of breast cancer screening among South Asian Immigrants. For example, surveys of South Asian women in Canada and England have revealed low rates of mammography screening, breast self-exam (BSE), and clinical breast exams (Bottorff, Johnson, Bhagat et al., 1998; Sutton, Storer & Rowe, 2001). The breast cancer-screening goal of the U.S. Department of Health and Human Services (2001) is that 70% all women aged 40 and older will have mammography by year 2010 (U. S. Department of Health and Human Services).

According to Bandura's social learning theory (SLT), the effectiveness and credibility of a message depends on the characteristics of the presenter (Bandura, 1977). A presenter who appears to share the values and beliefs of the audience is perceived as more credible and authentic. In this intervention, South Asian Indian women were used as characters in the video to represent women's experiences with breast cancer in realistic settings, and engage in actions designed to promote performance of recommended actions (efficacy expectations) by the participants.

The lack of breast cancer screening practices among South Asians may be related to a lack of knowledge about and access to screening facilities, as well as particular cultural beliefs and practices (Bottorff et al., 1998). This gap is of particular concern for countries with diverse populations such as USA, Canada, United Kingdom and New Zealand. There is a general consensus that the gaps in breast cancer screening rates need to be addressed by effective interventions aiming to reach vulnerable immigrant subpopulations. Although considerable efforts have focused on the development of breast cancer screening programs few programs have focused on South Asian women. Evidence suggests that South Asian immigrant women have limited knowledge about available breast cancer screening procedures and resources, and misinformation about causes and risk factors for breast cancer (Choudhry et al., 1998; Kernohan, 1996).

There exists a strong need for a culturally sensitive educational intervention program to increase breast cancer knowledge, decrease cancer fatalism and improve participation in breast cancer screening among South Asian women.

Problem Statement

Breast cancer is a major concern for all South Asian Indian Immigrant women (Bottorff et al., 1995). This may be related to lack of knowledge about cancer, combined with fatalistic attitudes, as well as particular cultural beliefs and practices. South Asian Indians are a comparatively new set of immigrants to the United States. They represent a wide variety of languages, dialects, and cultures as different from one another as from other Asian and non-Asian groups. Bottorff et al., (1998); & Johnson et al., (1999) reported that the majority of South Asian Indian women, both recent immigrants and those living in the United states for many years, had low levels of participation in cancer screening. Access to screening facilities may also be a problem. Although considerable efforts have focused on the development of breast cancer screening programs among women in general, few of these have focused on South Asian Indian women.

Purpose of the Study

The purpose of this study was to examine a culturally sensitive breast cancer educational video intervention on knowledge of breast cancer, cancer fatalism, and improved participation in mammography screening among South Asian Indian Immigrant women.

Research Hypotheses

Based on the research questions, four hypotheses were developed.

Hypothesis 1 - Participants viewing the video will have a greater increase in their Breast cancer knowledge test (BCKT) score compared to participants who read the brochure.

Hypothesis 2 - Participants viewing the video will have a greater decrease in cancer fatalism (CF) compared to participants who read the brochure.

Hypothesis 3- Participants viewing the video will show a greater increase in self-reported intention to seek mammography screening services compared to participants who read the brochure.

Hypothesis 4- Participants viewing the video will show a greater increase in seeking mammography screening services compared to participants who read the brochure.

Chapter II

REVIEW OF RELATED LITERATURE

Breast cancer is the most commonly diagnosed cancer in women. Sources indicate that one out of every nine women is likely to develop breast cancer (Spratt et al., 1995). The concern for breast cancer extends to all women. Considering the growing number of South Asian women residing in New Jersey, it is particularly important that we turn our attention to the health needs of this group. Majority of South Asians are from the subcontinent that comprises India, Pakistan and Bangladesh. However, because they originate from the same geographic region, South Asians share many cultural practices surrounding food, dress, ceremonies and cultural norms.

Current data regarding incidence of breast cancer among South Asian women living in United States is limited because breast cancer registries do not collect information on ethnicity. However, there is some evidence that South Asian women are not excluded from breast cancer. For example, an increased incidence of breast cancer among women in India has been reported, with over 60,000 new cases identified every year (Yeole et al., 1990; Nair et al., 1993). It is not unreasonable to suggest that breast cancer is also a significant health problem for South Asian women in New Jersey. Particularly, as the majority of South Asian women residing in New Jersey are immigrants. Breast cancer is becoming a major concern for many South Asian women as they witness family members,

friends and acquaintances in their community being diagnosed with and sometimes dying from, breast cancer.

Since the causes of breast cancer are as yet undetermined, the best approach to reducing the breast cancer mortality is early detection through breast self-examination, clinical breast examination by a trained health professional, and regular mammography screening. However research indicates that breast cancer screening programs are underutilized by ethnic communities (Lovejoy et al., 1989; Fox and Stein, 1991; Brownstein et al., 1992; Caplan et al., 1992; Vernon et al., 1992; Sodhi, 1995). Common barriers that prevent participation in breast screening programs include language, cultural beliefs, low socioeconomic status, and the lack of referral from a doctor. To date, most of the research has been conducted in the United States and has largely been limited to Hispanic, African-American, Chinese-American and low income women.

Clinical observations of women from a South Asian community living in western Canada suggest that there is limited use of breast health practices. This may be related to a lack of knowledge as well as particular cultural beliefs and practices. It is vitally important that factors such as ethnicity and cultural differences not preclude women from seeking and engaging in breast health practices. Indeed, we must ensure that services and educational messages are offered in culturally suitable ways. Health programs that provide services should be accounted for group's cultural values and beliefs in a context that is perceived as accessible, acceptable and supportive (Clarke, 1997).

There have been a few studies on South Asian women's cultural beliefs and values related to health (Bhopal, 1986; Nilchaikovit et al., 1993; Bhagat et al., 1995; Bhakta et al., 1995; Sodhi, 1995; Dhari et al., 1997). Researchers have identified factors that influence health choices for South Asian women. These include family structures, traditional behaviors, norms regarding appropriate behavior for women, modesty surrounding health concerns that are particular to women and attitudes about illness have a profound effect upon the health choices made by the members of this group.

In evaluating the effect of a breast awareness program among South Asian women living in England, researchers found that the majority of women did not perceive themselves at risk for cancer, believed that breast self-examination was not necessary, and were often shy about having male physicians examine their breasts (Bhakta et al., 1995). In a study on contraception practices in the South Asian community Day (1994) points to the importance that is placed on a women's dignity, resulting in women's hesitancy to be touched by a male physician or to disrobe for examinations.

Although screening facilitates the early detection of breast cancer and improves prognosis many women in North American and Europe remain underscreened this extends to immigrant women. Especially several studies have reported that immigrant women have lower breast cancer screening rates (Maxwell, Kozak, Desjardinis-Denault, & Parboosingh, 1997; Maxwell, Bancej, & Snider, 2001). Gaps in breast cancer screening rates need to be addressed by

effective health promotion interventions aiming to reach vulnerable immigrant subpopulations.

Many immigrants encounter economic, systemic, information, cultural, and linguistic barriers to access health services (Reitz, 1995). The extents of these challenges are often greater for immigrant women than men due to their multiple care-giving responsibilities that limit opportunities to obtain screening. George and Ramkissoon (1998) observed that South Asian immigrant women's childcare and household responsibilities are major reasons for neglecting self-health, especially for preventive practices when health benefits may seem distant. Other studies with South Asian immigrant women report cultural tendencies of strong familial orientation that result in low priority for self-care in the presence of competing demands (Bottorff et al., 1998; Chandarana & Pellizzari, 2001). This vulnerability is also manifested in studies reporting low cancer screening rates among South Asian immigrant women (Choudhry, Srivastava, & Fitch, 1998; Gupta, Kumar, & Stewart, 2002).

Review of the literature on breast cancer and screening among South Asian immigrant women reveals certain culturally based norms, beliefs and values that are likely to hinder their use of breast cancer screening practices (Bottorff et al., 1998; Johnson et al., 1999; Choudhry et al., 1998; Johnson et al., 1999).

Cancer fatalism

Cancer fatalism is the belief that death is inevitable when cancer is present (Powe, 1995a). Fatalism is believed to result from a complex psychological cycle characterized by perceptions of hopelessness, worthlessness, meaninglessness, powerlessness, and social despair (Freeman, 1989; Powe, 1995a; Weinrich & Weinrich, 1986; Weinrich, 1990 & West, 1993). For instance, tremendous fear of the disease is suggested in women's avoidance of the word "cancer" and preference to use "terminal life disease". The latter is also an expression of a culturally based fatalistic belief in which suffering is viewed as inevitable due to fate (karma).

Fatalism Research Using Similar Definitions

Bloom, Hayes, Saunders, and Flatt (1987) surveyed 568 black men and women in Northern California community to examine their cancer awareness, beliefs, attitudes, knowledge, and the use of cancer detection practices. The purpose of this study was to determine the community level of understanding of cancer and to design intervention strategies appropriate to the community's knowledge and level of understanding. The sample of 568 black adults included 317 women and 251 men. Educational levels of the sample were not reported. Data were collected from surveys completed as a part of the evaluation of a three to four year health education intervention program, and analyzed through frequency distributions and cross tabulations of measures of the demographic variables.

The researchers found that the majority of females surveyed were fatalistic. Most women believed “cancer was a death sentence for most people.” Only one question was used to assess fatalism which limits the generalization of the findings. This research represents the first study that suggested gender differences in the perception of fatalism.

Underwood (1992) investigated perceptions concerning cancer screening, cancer prevention, cancer risk factors, and cancer risk reduction among a non-randomly selected sample of 236 black males. Data were collected using a five part questionnaire developed by the researcher. The questionnaire focused on assessing empirical and conceptual variables of cancer risk and health care trends of black individuals. Data were analyzed using descriptive, chi-square, and co-relational statistics. Fatalism in this research was defined as “helplessness.” This definition is similar to the definition used in this study. The researcher concluded that men who were fatalistic were less likely to engage in early detection and risk reduction behaviors. In fact, 75% of the sample did not believe that early detection methods would significantly improve cancer survival. This finding also supports the negative relationship between fatalism and participation in cancer screening. This work linked ones fatalistic and pessimistic attitude about one’s health status to a decreased likelihood of engaging in health promotion activities. Individuals who hold fatalistic attitudes are less likely to engage in cancer risk reduction and early detection behaviors, and are less knowledgeable of the relationship between high-risk behavior and the development of cancer.

Powe (1995b) conducted a descriptive co-relational study on the relationship between selected demographic factors, fatalism, knowledge of colorectal cancer, and participation in fecal occult blood testing among 192 randomly selected poor, elderly, African Americans. Data were collected using a demographic questionnaire, the Powe Fatalism Inventory (PFI), the Colorectal Cancer Knowledge Questionnaire, and hemoccult kits. Correlations, *t*-tests, stepwise multiple regression and stepwise logistic regression were used to analyze the data. Results revealed that the typical fatalistic African American, female, had decreased education, annual income below the poverty level and decreased knowledge of colorectal cancer. Fatalism was a significant predictor of participation in Fecal Occult Blood testing. In fact, when fatalism was added to the statistical model, other previously supported predictors such as demographic factors and knowledge of colorectal cancer lost their significance.

In another similar study, Powe & Weinrich (1999) evaluated the effectiveness of a culturally sensitive video intervention in decreasing cancer fatalism, knowledge of colorectal cancer, and increasing participation in fecal-occult blood testing (FOBT). This study used repeated measures, pre-test/post-test design to measure these variables in a sample of 70 rural elders. Subjects were randomly assigned to a (video) intervention ($n=42$) or control ($n=28$) group. Findings from this study revealed that participants who viewed the culturally sensitive video had a significantly greater decrease in cancer fatalism scores than the control group

($F(1,65)=90232$; $p=0.003$) and a significantly greater increase in knowledge of colorectal cancer than the control group ($F(1,65) = 3.95$; $p=0.044$).

Another study conducted by Pignone, Harris & Kinsinger (2000) showed that a videotape coupled with educational brochures targeted to the patient's awareness to get screened significantly increased colon cancer screening. Fecal occult blood testing or flexible sigmoidoscopy was requested for almost half of the intervention participants (47%) versus approximately one-fourth of controls (26%). Also, over one-third (37%) of patients who received the intervention completed screening versus 23 % for controls. Pignone's results suggest that the videotapes encouraged patients to ask their provider about screening.

Knowledge of Breast Cancer

Evidence supports that knowledge about breast cancer is positively associated with increased likelihood of practicing breast self examination (National Cancer Institute 1980; Reeder, Berkanovic, & Marcus, 1980), receiving clinical breast examination (McCance et al., 1990), and undergoing mammography screening (McCance et al., 1990). While there is growing literature on the association between breast cancer knowledge, attitudes, and behavior, there are very few valid and reliable surveys that measure such knowledge.

Stillman and others (1977) developed a four-item survey to measure factual knowledge of breast cancer. This multiple choice survey is comprised of questions regarding factual knowledge about the prevalence, associated risk factors, and causes of breast cancer. Content validity was established by five

graduate nursing students and two non-nurses. The instrument was then tested on a convenience sample of 122 women aged 20 to 59 years of age.

Unfortunately, the researchers did not give information regarding the ethnic breakdown of the sample. While Stillman et al. (1977) reports that the pre-test demonstrated the instrument's success in obtaining the appropriate data, the method of item analysis is not clearly described. No reliability analyses were conducted on this tool.

Extending the work of Stillman (1977), McCance, et al. (1990) developed the Breast Cancer Knowledge Test (BCKT). The BCKT is an 18-item instrument that assesses knowledge about breast cancer screening. The authors reported that content validity was evaluated by four experts who included a medical oncologist and noted authority on public education programs for cancer control; a nurse researcher in health education; a medical oncologist who, at the time, was the president of the American Cancer Society (ACS); and a clinical nurse specialist and researcher in cancer nursing. The internal consistency reliability of the BCKT is .87 (pre-test) and .85 (post-test).

McCance et al. (1990) designed the BCKT to target interventions for promoting early breast cancer detection. McCance's work supports the use of BCKT applications in a variety of clinical settings, including primary care, the community, and the work place. For example, the BCKT can assist health professionals to design educational programs specific to the target populations,

surveyed can also be administered to evaluate the effectiveness of such educational interventions.

The Transtheoretical Model (TTM) and Health Belief Model (HBM)

Construction of the intervention was guided by the transtheoretical model (TTM) and the health belief model (HBM). The TTM ((Prochaska and Redding, 1997) proposes that people move through a series of progressively more committed stages of adoption when modifying a health-related behavior (i.e. screening behavior). The most effective method of detecting and reducing mortality from breast cancer is screening mammography. Several studies have applied The Transtheoretical Model to increase women's participating in mammography screening within a variety of populations. Following the lead of experts in the area of breast cancer screening, the defined stages of adoption are as following: pre-contemplation, contemplation, preparation, action and maintenance. Pre-contemplation has been defined as never having had a mammogram and not planning to have one within the next two years. Women in contemplation are those who never had a mammogram, but plan to have one in the coming two years. The action stage has been defined as having had one mammogram on schedule, and intending to have another on schedule, or already having one scheduled. Finally, the maintenance stage includes women who have had at least two mammograms on schedule and intend to have another on time. TTM is a dynamic theory of change. It must remain open to enhancements as more students, scientists, and

practitioners apply the stage paradigm to a growing number and diversity of theoretical issues and public health problems.

The HBM (Strecher and Rosenstock, 1997) describes how behavioral change is determined by several interacting components. The fundamental premise is that individuals will screen for an ill-health condition (e.g. cancer) if they recognize a threat. HBM and its constructs could be implemented for potential intervention strategies to increase mammography screening among South Asian Immigrant women. The HBM originated in 1950 from seminal research conducted by the United States Public Health Service. Social psychologists tried to explain the lack of participation of people in free health screening programs such as tuberculosis screening programs. According to this theory health behavior is a function of knowledge, attitudes and perceptions (Glanz et al., 2002). This theory states that there are two important factors that determine the likelihood of a person adopting the recommended health behavior. An individual's belief in his/her susceptibility and severity of the disease leads to health positive behavior. The other factor that controls possibility of behavior change is the person's belief that benefits of positive health behavior, in this study, getting mammogram outweigh the barriers. To address the issue of increasing mammography utilization; a health positive behavior, it is important to understand their beliefs and attitudes regarding breast cancer among South Asian Immigrant women. Understanding South Asian Immigrant women's views regarding benefits of mammography and barriers to getting screened will help in planning necessary interventions. Wong-Kin, Sun, &

DeMattos, 2003; Pham & McPhee, 1992) documented the knowledge, beliefs, and attitudes of Asian American women regarding breast cancer and screening for early detection. The findings suggested that lack of time, knowledge, transport, embarrassment and inability to understand English language were some of the barriers. Higher socioeconomic level, a physician's recommendation to obtain a mammogram, longer duration of residency in the United States and greater acculturation were associated positively with screening. In a study of health beliefs and practices related to breast cancer screening in Filipino, Chinese and Asian Indian women (Wu, West, Chen, & Hergert, 2006), results showed strong influence of ethnicity on perceived susceptibility and seriousness. The study also found that each ethnic group reported distinct barriers for getting mammograms. Chinese participants identified "I do not need mammogram if I feel ok" as a barrier. For Filipino women "waiting time is too long" was an important barrier, whereas for Asian Indian women "do not know where to get a mammogram" was a major barrier. This study involved 125 Asian American women out of whom 47 were Filipinos, 40 were Chinese, and 38 were Asian Indian women. A self-administered questionnaire was used to evaluate participants' knowledge, beliefs, and screening practices.

South Asian Indian Women, Breast Cancer and the Health Belief Model (HBM)

Rashidi and Rajaram (2001) explored the religious and sociocultural ramifications of breast cancer screening practices among this population. The study was conducted on 39 Asian Islamic immigrant women between the ages of 20 and 48 years. Results from the study were (a) the majority had never had a Clinical Breast Exam (CBE); (b) none of the women 40 years and older had ever had a mammogram; and (c) most of the women had heard of Breast Self Exam (BSE); however only one practiced BSE on a monthly basis. The study also stated that Asian Islamic women are less likely to perceive breast cancer as a serious threat or illness. Therefore, based on the Health Belief Model (HBM), these women will be less likely to practice any preventive breast care techniques (Rashidi & Rajaram).

Few studies have been done to examine the degree to which Asian Indian women understand breast cancer practices, and even fewer studies have utilized the HBM to study this population and breast cancer. Sadler et al., (2001) studied the breast cancer knowledge, attitudes, and screening practices of 194 American Asian Indian women. Results from the study indicated that (a) BSE adherence was 40.7%; (b) 54.8% had a CBE within the past 12 months; (c) 61.3% of the women 40 and over had a mammogram within the past 12 months; (d) 70% of the women 50 and older had a mammogram within the past 12 months. The authors noted that these rates were relatively high. This reason may be attributed to the fact that the women who consented to participate in the survey were more

acculturated and from a higher socioeconomic status. Thus the screening practices, attitudes, and behaviors of the women in the study should not be relied upon to represent all Asian Indian women in the United States nor in India.

In this study, Choudhry et al. (1998) used the variables of the HBM to explore the knowledge, attitudes, beliefs, and practices regarding breast cancer detection among Asian Indian women in Canada. A questionnaire was used to obtain data from 57 first generation immigrant Asian Indian women 40 years and older. The results indicated that (a) 54% stated they did not know very much about breast cancer. (b) 49% had undergone at least one CBE in their lifetime; (c) 47% had never had a mammogram; and (d) 12% of participants practiced BSE; For example, only 21% of the participants believed detecting cancer early was important, while only 5% believed that cancer could be cured.

Culturally Sensitive Breast Cancer Educational Materials

Researchers attribute the increase in survival rates for many cancers to cancer education (ACS, 1997; Freeman et al., 1995). Cancer education materials are used to reiterate verbal communication, strengthen the teaching process, reinforce learning, enhance compliance (Glantz & Rudd, 1990; Jubelirer, 1991), and increase knowledge about cancer prevention and detection (Allensworth & Luther, 1986; Rankin & Stallings, 1996; Redman, 1997).

While the South Asian public is regularly exposed to cancer prevention messages through communication media much of the prevailing information is culturally irrelevant and presented at high reading levels (Black, 1995; Doak et al.,

1996; Guidry & Fagan, 1997, Guidry et al., 1998; Jackson et al., 1991; Michielutte et al., 1992; Plimpton & Root, 1994). In order for cancer educational materials and interventions to affect positive health practices, such materials must be relevant to the population in terms of readability and cultural sensitivity (Doak et al., 1996; Guidry et al., 1998; Jackson et al., 1991; Michielutte et al., 1992; Plimpton & Root, 1994; Black, 1995).

One new medium for conveying information about mammography is with videotapes. Video presentations that focus on specific health conditions (breast cancer) and screening options (mammography, breast self-exam, etc.) appear to be more effective in promoting cancer screening (Valdez et al., 2001). Another study measured behavioral outcomes of a video-based program on breast self-exam and found that breast self-exam skills of study participants improved significantly (Wood, 1996). These studies suggest that videotapes have considerable potential to convince women of the benefits of mammography screening.

Although considerable efforts have focused on the developments of breast cancer screening programs for women in general, few of these have focused on South Asian Indian women. The few studies that have reported on breast cancer awareness and screening compliance among South Asian Indian Women living outside of India were conducted outside the United States. Those studies reported low levels of knowledge of breast health and screening guidelines. For example monthly breast self exam adherence rates are as low as 12% in Canada

(Choudhry et al., 1998; Hoare, 1996; Hoare et al., 1994; Kernohan, 1996).

Interestingly an evaluation of my pilot study (2007) surveyed 30 South Asian Indian Immigrant women (Kumar et al., 2009). Survey findings, indicated that South Asian Indian immigrant women had 42% level of knowledge about breast cancer risk factors. More than half of the women did not utilize mammography screening. Modesty and lack of family support were two important cultural barriers identified by the participants.

Several studies report that immigrant women have lower breast cancer screening rates (Maxwell, Desjardins-Denault, & Parboosing, 1997; Maxwell, Bancej, & Snider, 2001). This gap is of particular concern for countries with increasing population diversity such as United States, Canada, United Kingdom and New Zealand. There is a general consensus that gaps in breast cancer screening rates need to be addressed by effective interventions aiming to reach immigrant subpopulations. Evidence also suggests that South Asian Indian Immigrant women have limited knowledge about available breast cancer screening procedures and misinformation about its causes and risk factors (Choudry et al., 1998; Kernohan, 1996). There exists a strong need for a culturally sensitive educational program to increase breast cancer knowledge, decrease cancer fatalism and improve participation in breast cancer screening among South Asian Indian immigrant women. Therefore the purpose of this study was to examine the effectiveness of a culturally sensitive educational video on knowledge of breast cancer, cancer fatalism, and improve screening

intention/participation in mammography screening among South Asian Indian immigrant women.

Chapter III

METHODOLOGY

Subjects:

Approval from the Seton Hall University Institutional Review Board (SHU-IRB) was obtained before subject selection began. The study population was composed of 102 community dwelling (fifty one in each group) South Asian Indian immigrant women residing in New Jersey. The study included only South Asian Indian immigrant women who were born in India and migrated to the U.S. and not those women who were born in United States. The sample size of one hundred and two subjects was based on Cohen's (1988) table for Analysis of Variance (ANOVA) as well as power analysis using G * power 3. For an ANOVA, with an alpha level of .05, a medium effect size of .30 and a power of .80, (Faul, Erdfelder, 1992) a total of 102 subjects were required. This sample size is also consistent with other studies that suggested a peer-group educational program can significantly improve breast cancer-related knowledge and attitudes (Young & Sarna, 2003).

Setting:

The study was carried out in the hall of a local temple in suburban community of New Jersey. The president and the priest of the temple gave

permission for the study. The director of the local community temple assisted in announcing this study program and encouraged women to participate in the study.

Inclusion Criteria:

Inclusion criteria included the following: (1) South Asian Indian Immigrant Women 40 years or older who were born in India but now reside in New Jersey must have been born in India (2) Eligible participants must have completed most of their education in India and be able to understand and speak English. The age limitation is based on the American Cancer Society's recommendation that females begin having mammograms at forty years of age (ACS, 2008).

Exclusion Criteria:

Exclusion criteria included the following: (1) South Asian Indian immigrant women who had a mammogram in the previous 12 months and (2) South Asian Indian immigrant women with breast cancer.

Design and Variables:

This study was a quasi-experimental pre-posttest, follow-up design. The survey method of self-completion of questionnaire was used for data collection. The questions included in this survey were formatted to assess knowledge of breast cancer, cancer fatalism and screening intention to participate in mammography screening.

The dependent variables included breast cancer knowledge test scores, cancer fatalism scores and screening intention/participation scores. The independent variables were Pre-Post test and the intervention which had two levels: (1) video intervention, and (2) brochure intervention.

Instrumentation:

Data was collected using a Demographic Questionnaire (Appendix F), including The Breast Cancer Knowledge Test (McCance et al, 1990) and the Powe Fatalism Inventory (Powe, 1995a). Permission to use these instruments was obtained by email from the developer of these tools.

Demographic/Screening Practice Questionnaire

A demographic questionnaire which was comprised of 18 items (Appendix F) was given at the beginning of the study to determine date of birth, educational level, employment, marital status, and health insurance. In addition, participants were asked if they had previously participated in breast cancer screening and detection activities such as clinical breast exam (CBE) and mammography.

The Breast Cancer Knowledge Test:

The Breast Cancer Knowledge Test (BCKT) was developed by (McCance et al, 1990) to measure a woman's knowledge of breast cancer screening and detection activities. This instrument was also designed to determine the relationship between breast cancer knowledge and detection practices. The BCKT is an 18-item inventory, which is scored using a combination of true/false and multiple choice questions. The level of measurement is a nominal scale and coded to an interval scale. Every answer in the scale was coded "1" if the respondent provided the correct answer and "0" if an incorrect answer was given. Individual scores were expressed as the percentage of correct answers. Therefore, higher scores on the BCKT (McCance et al, 1990) are indicative of greater knowledge of breast cancer screening and detection. The authors reported that content validity was evaluated by four experts who included a medical oncologist and noted authority on public education programs for cancer control; a nurse researcher in health education; a medical oncologist who, at the time, was president of the American Cancer Society (ACS); and a clinical nurse specialist and researcher in cancer nursing. The Cronbach alpha reliability of the BCKT are .87 (pretest) and .85 (posttest).

Powe Fatalism Inventory

The Powe Fatalism Inventory (PFI) was developed by Powe (1995a) to assess the presence of fatalism. It is 15 items questionnaire that defines attributes of cancer fatalism (fear, pessimism, predetermination, and inevitability of death). Items on the PFI can be answered “yes”, or “no”, with a possible range of scores of 0-15. The level of measurement is a nominal scale and can be recoded to interval scale. Respondents were given one point for each “yes” response. Higher scores on the PFI (Powe, 1995a) are indicative of higher levels of fatalism. The PFI (Powe, 1995a) had a Cronbach alpha reliability of 0.87 during pilot testing. The PFI has had reliability coefficients ranging from 0.84 to 0.89 when used with previous samples (Powe, 1995a, Powe, 1995b). Content validity, reading level, and clarity of the PFI (Powe, 1995a) were evaluated by four nursing experts. Two of the four experts were doctoral prepared nurse researchers who were experienced in tool development and also familiar with the study population. The other two experts were professional nurses actively working with the study population of African Americans. These experts verified content validity and clarity of the PFI (Powe, 1995a).

Procedures

Following approval of the research protocol by the Seton Hall University's Institutional Review Board, participants were solicited through flyers posted in temples of New Jersey. Women who were interested in the study contacted the principal investigator via telephone, Women that meet inclusion criteria were placed in 1:1 random assignment. First call Odd number was placed to the Brochure group (1) and Evens to the Video group (2) Inclusion and Exclusion criteria was reviewed verbally using the screening tool. Once the individual indicated willingness to participate in the study and if eligible, the participant signed an informed consent and was assigned their own confidential unique identification number (Appendix E).

A unique identification code was assigned to track the number of participants enrolled and for data entry. To maintain confidentiality, all questionnaires were marked with the subjects' identification number. After screening the participants using screening tool (Appendix D). The participants were then directed to the private room. The participants did not take the questionnaires home. The same day the participants read the letter of consent signed and completed the survey. The study took place through the month of January and March of 2009 at a temple in the suburban area of New Jersey. The sequence of topics covered in the survey was as follows: Pre-test (a) Knowledge of breast cancer test; pre-test (b) Powe fatalism test (c) and demographics. These questionnaires were given to women at the Temple to either a Group 1 (Brochure-

group) or Group 2 (Video- group). After a brief introduction by the investigator regarding the study, participants who volunteered were asked to complete the survey. They were placed in a well -lit private room with the door closed and free from distraction. The chairs and tables were placed in a U-style and subjects were asked to sit in every other chair to complete the survey. Both groups were asked to come on their assigned days. Completed pretest questions were returned via the drop off box located in the corner of the room. After this the participants assigned to the Group-1 (Brochure) received brochure from American Cancer Society (ACS) explaining mammogram, Clinical breast exam (CBE), Breast self exam (BSE), ACS guidelines and resources to receive mammogram. They were asked to carefully read the brochure, which took 16 minutes. Participants assigned to Group-2 (Video) viewed a video from New Jersey Cancer Education and Early Detection (NJCEED) which was designed to be culturally sensitive to South Asian Indian Immigrant Women (SAIIW). The video included the following: risk of breast cancer, the importance of early detection, the disease of breast cancer, concerns about breast cancer screening, the mammogram, the breast self-exam, what if abnormalities are detected, questions for one's doctor, and the importance of a men giving testimony about their wife's experience. Fear about mammography was directly addressed in the segment and consequences of not having a mammogram were also covered in the video. The video was viewed for 16 minutes and was narrated in English, tailored for two age groups (South Asian women under and over 40 years of age) General information (statistics) on breast

cancer including risk factors and methods of detection (BSE, CBE, mammography) and treatment (surgery, chemotherapy, radiation therapy);

- 1) Clarification of myths and misconceptions that individuals may have about breast cancer (cancer is a death sentence and cannot be treated);
- 2) Identification of facts concerning breast health (early detection of breast cancer leads to survival and or improved quality of life) is covered.

There were six sessions on each assigned day. Each session lasted approximately 40-45 minutes. On average, each session had 7-8 individuals at a given time. Participants were not given an opportunity to ask questions, and both groups came in on separate days. Participants were allowed to attend the session anytime between the hours of 10:30 am and 8:30 pm. Allowing participants to choose their own time to participate may increase the informality of the program, and demonstrated sensitivity to the schedules of busy people. This allowed working women to come during their lunch hours and homemakers to make arrangements to have their responsibilities covered by someone else for a specific period. Participants were not allowed to ask questions or talk among themselves. Both the brochure and the video covered the same information, but presented in a different medium.

Brochure and Video group participants were then asked to complete both the PFI and the BCKT posttest after the intervention. At the end participants were given a Pretest screening intention questionnaire. Behavioral intent was measured using three items: intention to seek information about breast cancer, asking their

physician about a mammogram, and obtaining a mammogram in the near future (within three months). At the 90 day mark, the principal investigator mailed out a follow up screening intention/participation questionnaire with one added question in a self addressed envelope to ascertain mammography status.

Data Analysis:

SPSS Version 14.0 (SPSS, 2005) was used for the data analysis. Descriptive and inferential statistics were used to analyze the data. The demographic data were analyzed using frequency and counts. Frequencies and percentages were used to describe age, education, employment status, marital status, and the participant's responses to questions regarding health knowledge. Pretest and Post-test measures included the Breast Cancer Knowledge Test, and the Powe Fatalism Inventory. Chi-square test was used for comparison of categorical variables. A 2X2 ANOVA with 51 participants per cell was conducted with pretest/posttest as the within subjects factor and treatment (brochure or Video) as the between subjects factor. A "p" value <0.05 was considered statistically significant.

Chapter IV

Results

Participants

104 South Asian Indian Immigrant women, forty years of age and older volunteered to participate in the study at a temple in the community of Northern New Jersey. Of the 104 questionnaires administered, there were two fallouts. These participants received an emergency call and had to leave the study. The characteristics of study participants are shown in Table 1. All the study participants were immigrants from the Country of India and were between 40 and 73 years old. The women's mean age in the brochure group was 53.10 years and the women's mean age in the video group was 51.5 years. 100% of all participants were born in India. Most of the women living in the United States between 2 and 6 years with nearly 20% of each group are living in the United States 10 years or more. Table 1 shows that participants were significantly different only in their marital status. Nearly all of the women in the video group 50 (98%) were married. 42 (82.4%) of the brochure group were married ($p = 0.018$).

Table 1

Demographic Comparison of the Participants in Both Groups (N=102)

Characteristics	Brochure group <i>n</i> =51	Video group <i>n</i> =51	p-value
Place of birth	India	India	
Age, year (mean \pm SD)	53.10 \pm 8.4	51.5 \pm 5.5	p=0.257
Age (moved to the United States)	47.3 \pm 8.1	45.2 \pm 9.3	p=0.233
Number of Years Living in the 2-6years	29 (56.9%)	35 (68.6%)	p=0.510
Marital Status: Married	42 (82.4%)	50 (98.0%)	p=0.018*
Years of schooling: High school	25 (49.0%)	33 (64.7%)	p=0.260
Current employment Unemployed	38 (74.5%)	37 (72.5%)	p=.836
Uninsured	35 (68.6%)	42 (82.4%)	p=.107

Data are presented as mean, Standard Deviation, number of subjects, percentages and p-values. *Significant difference was noted in marital status.

General Breast Cancer Health Knowledge

Prior to any information sharing (brochure or video) a pre-test was given to assess participants' level of mammogram knowledge. 43 (84.3%) of the 51 South Asian Indian Immigrant SAll women in the brochure group reported that they heard of a mammogram, where as 48 (94.1%) of the 51 (SAll) women in the video group reported that they heard of a mammogram (see Table 2).

Interestingly, participants in the brochure group had less breast cancer knowledge than participants in the video group. 35 (68.6%) compared to 46 (90.2%), respectively. This difference was found to be statistically significant ($p=0.007$ (see Table 2). When asked, why women have mammograms? Several reasons provided as options include to check for lumps, part of physical exam, family history, and check for cancer, doctor's order, and other.

The majority of respondents do not think they are at risk for breast cancer, and they believe Doctors have the authority to refer women to have mammograms. In the brochure group none of them had an annual mammography for over a two year period. Only 4 (28.6%) of them had mammography less than 3 years ago in the video group.

Table 2

General Breast Cancer Health Knowledge

	Brochure group n=51	Video group n=51	p=value
Ever heard of a mammogram? Yes	43 (84.3%)	48 (94.1%)	p=0.110
Do you know what a mammogram is? Yes	35 (68.6%)	46 (90.2%)	p=.007*
Can a women get cancer in the breast? Yes	46 (90.2%)	51 (100%)	p=.056
Why do women have mammograms: Doctors order	48 (94.1%)	44 (86.3%)	p=.183
Chance someday get breast cancer No	47 (92.2%)	35 (68.6%)	p=.003
When was your last mammogram Less than 3 years ago	0 (0.0%)	4 (28.6%)	p=.280

Data are presented as number of subjects, percentages and p=values
*Significant difference noted.

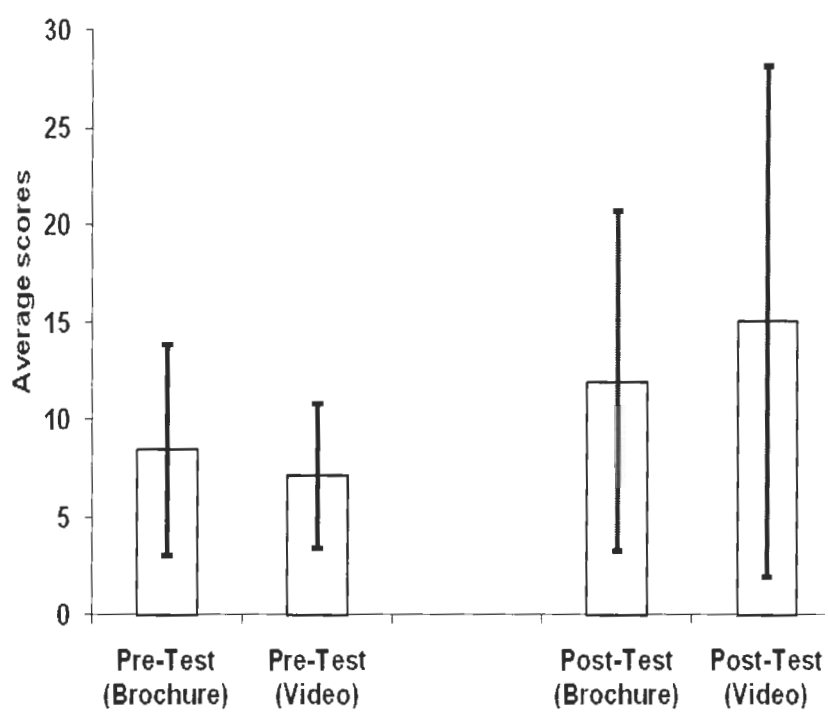


Figure 1 Average breast cancer knowledge test score by intervention group

Hypothesis 1- Participants viewing the video will have a greater increase in their BCKT score compared to participants who read the brochure.

The repeated factor in ANOVA are called within subject factor and grouping Factors in ANOVA are called between subject factors. So 2x2 mixed model ANOVA contain both with and between subject factors. A 2X2 mixed model of analysis with 51 participants per cell was conducted to study the effect of intervention (brochure or video) with pretest and posttest for within subjects factor and between subjects' factor. The results of the ANOVA indicate that there is a statistically significant interaction between test and intervention, $F(1,100) = 62.09$ $p < .0005$ suggesting that the relative performance on the two tests differed by intervention group. There was also a statistically significant main effect of test, $F(1, 100) = 316.54$, $p < .0005$, but not a statistically significant main effect for group by itself $F(1,100)=3.79$, $p = .054$. but yet the term group factor is significant ($p=0.000$). For both groups (video and brochure) there is significantly increase in breast cancer knowledge, but the effect is larger for the video group. The Video group had a mean pretest BCKT score of 6.3 (SD=3.4) and the brochure group had a mean pretest BCKT score of 8.3 (SD=3.0). At posttest, the video groups' mean BCKT score had increased to 15.3 (SD=1.9) while the brochure group increased their mean BCKT score to 11.8 (SD=3.2).

In this analysis the video group initially scored lower than the brochure group and then scored higher on the posttest. This finding does support my hypothesis that participants viewing the video will have greater increase in their BCKT score compared to participants who read the brochure.

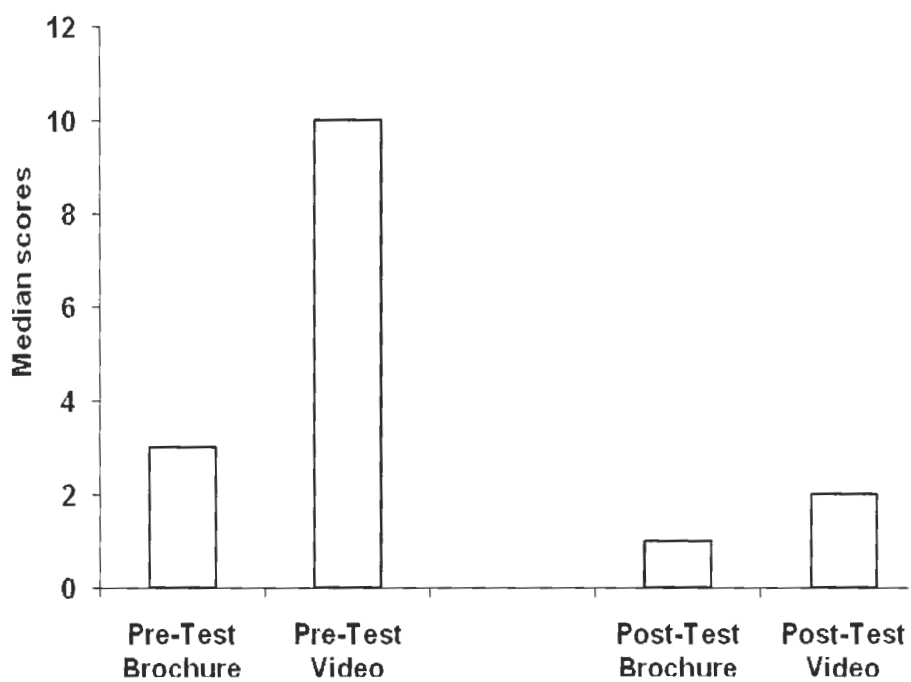


Figure 2 Powe fatalism test score by intervention group

Hypothesis 2 - Participants viewing the video will have greater decrease in cancer fatalism (CF) compared to participants who read the brochure.

Median cancer fatalism score of pre and post intervention groups were analyzed using Wilcoxon Signed ranks Test (within the groups) and Mann-Whitney U test (between the groups).

The brochure group had a median pretest cancer fatalism score of 3.0 and the video group had a median score of 10.0. At posttest, the video group's median cancer fatalism score had decreased to 2.0 and the posttest of brochure group had a median CF score that decreased to 1.0. The video group did not significantly show greater decrease in cancer fatalism scores than the brochure group ($p=0.691$). The participants hit the floor effect in the posttest brochure group. Floor Effect-means a measurement limitation of an instrument whereby the scale cannot determine decreased performance beyond a certain level. Even though brochure started off with decrease in cancer fatalism, video group still showed greater decrease in their fatalistic belief than brochure group even though the difference was not significant and did not support the hypothesis 2.

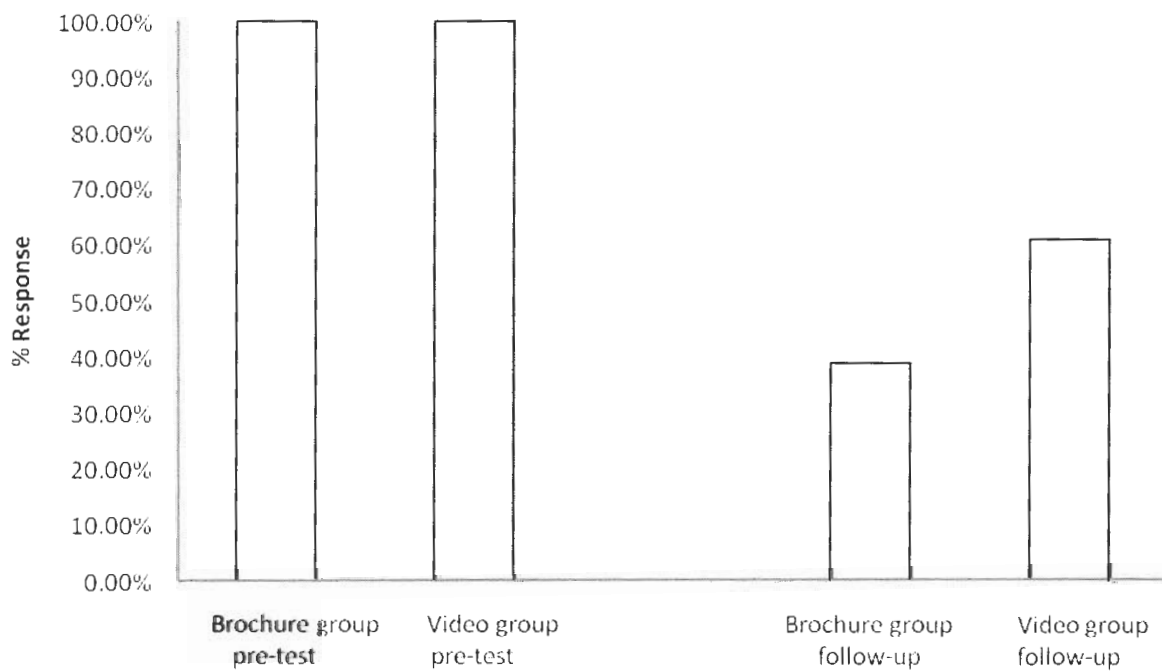


Figure 3 Intentions to seek mammography

Hypothesis 3- Participants viewing the video will have greater increase in self-reported intention to seek mammography screening services compared to those who read the brochure.

Differences between the groups who sought mammography were analyzed using Chi square test for categorical variables.

Both groups reported (100%) intention of having mammography screening in the pretest. Intention to seek mammography response in the follow up brochure group was 39.0% and the follow up video group was 61.1%. No significant group differences was found for intention to obtain a mammogram within the near future between the two groups at the follow up ($X^2 = 3.07; df=1; p=.079$). No significant group differences was found with respect to the intention to ask a doctor about getting a mammogram referral ($p=.099$). A significant difference between the groups was found only with respect to seeking information about breast cancer ($p=.015$). These findings did not support hypothesis #3 that participants viewing the video will have greater increase in self-reported intention to seek mammography screening services compared to participants who read the brochure.

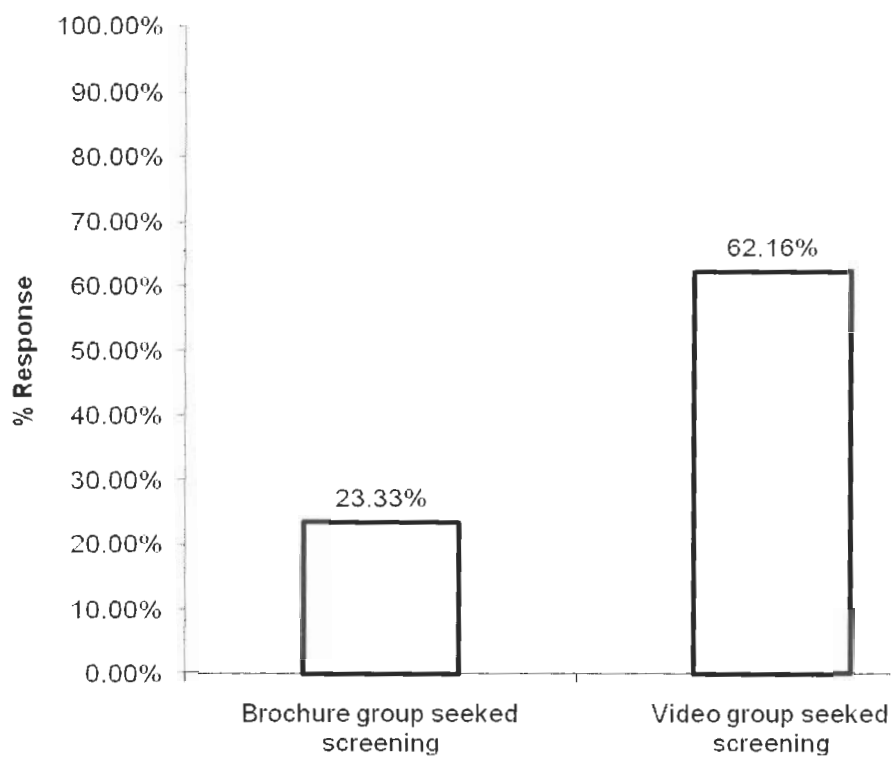


Figure 4 Percentage of participants who sought out mammography screening

Hypothesis 4 - Participants viewing the video will show greater increase in seeking mammography screening services compared to participants who read the brochure.

The majority 23 (62%) in the video group participated in seeking mammography services compared to 7 (23%) in the brochure group. Both the brochure group and video group reported seeking mammography. Three times greater increase sought in mammography screening was seen among participants in the video group. Chi square of mammography sought showed significant difference between the brochure and the video groups ($X^2=8.80$; $df = 1$; $p=.006$). Our data did support the hypothesis #4. Participants viewing the video showed a greater increase in screening participation than the brochure group.

Chapter V

Discussion

According to SEERS data for the period 1990-1997, breast cancer was the leading cause of cancer deaths among women of all racial/ethnic backgrounds. Early detection of breast cancer currently offers women the best chances for survival in the absence of well-established primary prevention strategies. In this study the use of a South Asian Indian culturally sensitive breast cancer educational video, increased South Asian Indian women's knowledge of mammogram. This finding is important as it is consistent with the Health Belief Model data, more knowledge of breast cancer has been associated with greater mammography use, more frequent clinical breast examinations (McCance et al., 1990), and more frequent BSE (Champion, 1987; Dickson et al., 1986; Gray, 1990; Mamon & Zapka, 1986; Reeder, Berkanovic, & Marcus, 1980; Rutledge, Barevick, Knobf, & Bookbinder, 2001).

Findings from this study indicated that participants assigned to the video group had a statistically significant increase in knowledge of breast cancer compared to those individuals who were assigned to the brochure group. Both groups had significantly higher post test mean knowledge scores than pre-test scores. The video group scored lower on the pretest, but better on the posttest, the brochure group. The video group had a much greater increase when comparing difference scores. In this analysis the video group initially scored lower

than the brochure group and then scored higher on the posttest and the findings support my hypothesis that participants viewing the video will have greater increase in their BCKT score compared to participants who read the brochure.

In reviewing specific items, both groups knew mammogram could detect lumps that they, themselves could not find, and that a mammogram was the best method for early detection. Although knowledge was increased after the interventions, there continued to be some uncertainty even among participants after the interventions (video or brochure) as to whether women were always able to find lumps in their breast. An interesting point to note is that both the groups knew the recommended frequency for getting a mammogram.

Kumar et al. (2009) study revealed that South Asian Indian immigrant women had fatalistic attitude towards cancer, barriers, fear of cancer, and were embarrassed to go for breast and mammography screening. The results of the present study did not support the hypothesis that SAI women, who received a culturally sensitive video presentation on breast cancer, would be less fatalistic about cancer than those participants who received a brochure intervention. When looking at fatalism scores after the interventions those participants in the video group did not show a statistically significant decrease in fatalism scores when compared with those participants in the brochure group. Sampling error was observed from the Powe Fatalism Survey. The participants hit the floor effect (Portney & Watkins 2000) in the posttest brochure group. Even though brochure group started off with decrease in cancer fatalism, video group still showed greater

decrease in their fatalistic belief than the brochure group though the difference was not significant and did not support the hypothesis.

However, Powe & Weinrich (1999) evaluated the effectiveness of a culturally sensitive video intervention in decreasing cancer fatalism. Findings from their study revealed that participants who viewed the culturally sensitive intervention video had a significantly greater decrease in cancer fatalism scores than the control group ($F(1, 65) = 90.232; p = 0.003$). Our study did not prove that probably because they hit the floor effect which means a measurement limitation of an instrument whereby the scale cannot determine decreased performance beyond a certain level. Fear of mammography appears to stem from deeply held beliefs that cannot be changed through a single educational session.

Low rates of breast cancer screening have also been related to cultural values of fatalism. However, the results of this study indicated that women believed "if they developed breast cancer they will die. For instance, tremendous fear of the disease is suggested in women's avoidance of the word "cancer" and preference to use "terminal life disease". The latter is also an expression of a culturally based fatalistic belief in which suffering is viewed as inevitable due to fate (karma).

Tang et al. (1999) found that the Caucasian women compared to Asian women, were more open about their bodies and sexuality, had better communication with their mothers regarding screening and gynecological health, and having mindset oriented towards disease prevention. In South Asian culture,

modesty is a great virtue and if woman was modest, she would take control of her body by not performing BSE. A main barrier towards breast cancer screening was that those believed that getting an illness is a matter of karma were less likely to go for breast cancer screening than those who did not believe in karma. By definition, karma is the “force generated by a person’s actions held in Hinduism and Buddhism to perpetuate transmigration and in its ethical consequences to determine the nature of the person’s next existence” (Merriam-webster, 2003).

Finally, exposure to the intervention greatly increased the likelihood of obtaining mammogram. In the video group, 37 out of 51 responses were received out of which 23 (62.16%) participants sought mammography. In the brochure group out of 51 participants, 30 responses were received out of which 7 (23.33%) participants sought mammography. A more important greater finding was that both the interventions resulted in seeking mammography screening. Regardless of group assignments the women reported greater intent to seek mammography. Video group sought out mammography screening three times more than the brochure groups leaving us the question why?

This question fits the theoretical framework of Transtheoretical model as well as Social Learning Theory. TTM is a model used to increase participation in mammography screening and is dynamic theory of change. Change as a process involves progress and goes through a series of stages. Participants who were in the contemplating stage moved to the preparation stage and took cues to action and promoted positive behavior.

According to Social learning Theory, a video health education message's effectiveness and credibility depends on the characteristics of the presenter. A presenter who appears to share the values and beliefs of the audience is perceived as more credible and authentic. By watching the video they are observing the actions and outcomes of others behavior modeling and there is Self-efficacy- a person's confidence in performing a behavior and reminders are cues to action to get screening and will be motivated to make a positive behavior change. In this video intervention, South Asian Indian immigrant breast cancer survivors spoke of experiences with breast cancer in realistic settings, and engage in actions designed to promote performance of recommended actions (self-efficacy) by the audience. The videotape, which was targeted specifically for this population was designed to demystify the mammography procedure and emphasize the benefits of screening through stories told by real women, including those for whom breast cancer was detected early by mammography. The videotape also addressed the fears, risks, and barriers associated with mammography for South Asian Indian immigrant women.

This is the first research study conducted which examined the effects of breast cancer education on knowledge of breast cancer in the South Asian Indian population. This is also the first study to use culturally sensitive tools tested on South Asian Indian immigrant women.

These results are comparable to other interventions that employ similar educational methodologies, i.e., culturally appropriate video-based health

education material. Valdez, Banaerjee, Fernandez, and Ackerson (2001) evaluated the effectiveness of an interactive multimedia breast cancer education program based on Bandura's (1986) social learning theory with low-income Hispanic women. Information about breast cancer and barriers to screening and mammography was provided through video, music and audio. At a four-month follow-up, approximately 40% of the participants who had obtained or scheduled a mammogram since receiving the intervention attributed the decision to their participation in the program. In a similar study, the same researchers (2002) examined the effectiveness of a multimedia breast cancer education program based on Bandura's social learning theory. Low-income Hispanic women were assigned randomly to an experimental or control group. Women in the experimental group exhibited greater knowledge and were more likely to seek information about mammograms than were women in the control group (Valdez, et al., 2002).

There is some evidence that video-based methods are helpful in shaping health behavior of patients. For example, a video-based educational presentation on gonorrhea significantly increased the number of minority men who returned for a test-of-cure examination (Soloman, et al., 1988).

The multifaceted, culturally sensitive, breast cancer education presentation used in this study, resulted in an increase in knowledge of breast cancer. The program was effective in informing women about breast cancer and seeking mammography. The interventions encouraged the participants to contemplate the

personal value of following the recommended breast cancer screening guidelines. The interventions included that the women consult with their health care provider for more information and assistance accessing screening services.

Limitations and Future Research

The author recognizes there are limitations to the present study. Whether the findings of this study would generalize to South Asian Indian Immigrant women in a different geographic area is unknown. Replication of the program is needed to evaluate the generalization of the intervention. Sampling error was seen in the Powe fatalism survey. Participants hit the floor effect since the participating subjects were not selected randomly. Participants were volunteers from the temple and assigned randomly to one of the groups. The significant increase in intention to obtain a mammogram after viewing the video may be artificially inflated. It is possible that participating women would give their positive responses to encourage the researcher's effort in promoting breast cancer awareness and prevention. Another limitation, the breast cancer knowledge and cancer fatalism questionnaire were self-reported surveys, which can be opened to biased responses. The participants may have wanted to assist the researcher in finding a significant increase in breast cancer knowledge and decrease in cancer fatalism after the interventions, therefore answering the post-test questions accordingly. A major limitation of this study was the lack of long-term follow-up.

The 3-month follow-up was short time to indicate a sustained effect on behavior change.

In the future, the questionnaire should be administered in different locations. Other delivery methods such as showing the video (or distributing the brochure) in physician offices or other settings may be more likely to reach women who would not ordinarily read or watch the materials. Increasing awareness and participation of free mammogram programs that are available in the area is recommended. Also to include a certified practitioner to provide hands on BSE skills with teaching models. It is imperative that health care professionals and educators find effective methods for increasing the utilization of early screening practices for breast cancer.

Chapter VI

Conclusions

Delivering culturally sensitive video where South Asian Indian women gather at the temple is more effective. Early detection and prompt treatment offer the greatest chance of long-term survival. Nurses must play an important role in making breast cancer education accessible to underserved population (Olsen & Frank-Stromborg, 1993). Providing breast cancer screening to South Asian Indian women in the United States is challenging; increasing knowledge and changing faulty beliefs associated with screening are needed to increase mammography in the population. Educational programs for the South Asian Indian women, however, must be culturally based and appropriate to be successful. In addition, careful evaluation of the effectiveness of programs is necessary. Program success was increased through collaborative partnerships with the community at the temples. Community health facilitators provide informal, spontaneous assistance, which is so much a part of everyday life that its value is often not recognized. Collaborators or facilitators generally functions as mediators, social networks, and social support (Israel, B.A., Schulz, A.J., Parker, E.A., & Becker, A.B. (1998). They can influence the community's use of formal health services through a variety of processes by supplying information and advice, referring women for services, and providing cues as to the social acceptability of the health services (Brownstein, Cheal, Ackermann, Bassford, & Campos-Outcalt, 1992). In

addition, community health facilitators can provide professionals with an understanding of the community's priorities and health concerns.

The videotape intervention which targeted specifically this population, was successful to demystify the mammography procedure and emphasize the benefits of screening through stories told by real women (i.e., not actresses), including for whom breast cancer was detected early by mammography. The videotape also addressed the fears, risks, and barriers associated with mammography consistent with this population. This study suggests that the video used for this project may be a useful tool to increase rates of mammography screening than an educational brochure. New medium for conveying information about mammography is with videotapes. Videotapes can offer an advantage over written material in their ability to graphically present information and explain difficult concepts, which may help impart knowledge to those who are less literate (Mcade, et al.1994). They can also portray real-life situations and are particularly effective at reaching people on an affective or emotional level (Breckon, et al. 1994). Previous studies have shown that videotapes enhance patients' short-term knowledge (Cassileth, et al. 1982 and Stone, et al. 1989) reduce anxiety, fear, and pain associated with a medical condition (Gagliano, et al 1988) and are preferred over written material (Partridge, 1986). Video presentations have consistently been rated as better vehicles for the dissemination of information than posters, pamphlets, and other written materials (Mcade, et al. 1994). These characteristics suggest that

videotapes have considerable potential to convince women of the benefits of mammography screening.

In conclusion, the videotape used for this study had more significant effect on increasing mammography screening among women aged 40 and above. This study has also shown that the use of culturally sensitive breast cancer educational video can positively affect the knowledge and beliefs of South Asian Indian women.

References

- American Cancer Society. (2008). Cancer facts and figures 2008. Retrieved April 17, 2008, from <http://www.cancer.org/downloads/STT/CAFF2008PWSecured.pdf>
- Census Bureau. (2000). *The Asian population 2000: Census 2000 brief*. Retrieved November 16, 2006, from <http://www.census.gov/prod/2002pubs/c2kbr01-16.pdf>
- Bandura, A. (1977). Self-efficacy: toward an unifying theory of behavioral change. *Psychology Review*, 84, 191-215.
- Breckon, D. J., Harvey, J.R., Lancaster, R.B. (1994) *Community health education: settings, roles, and skills for the 21st century*. Third ed. Gaithersburg, MD: Aspen
- Brownstein, J.N., Cheal, N., Ackermann, S.P., Bassford, T.L. & Campos-Outcalt, D. (1992). Breast and cervical cancer screening in minority populations: a model for using lay health educators. *Journal of Cancer Education*, 7(4), 321-326.
- Bottorff, J.L. (1998). Beliefs related to breast health practices: The perceptions of South Asian women living in Canada. *Social Science Medicine*, 47(12), 2075-2085.
- Cassileth, B.R, Heiberger, R.M., March, V, Sutton-Smith, K. (1982) Effect of audiovisual cancer programs on patients and families. *Journal of Medical Education*, 57, 54-59.
- Choudhry, U.K., Srivastava, R. & Fitch, M.I. (1998). Breast cancer detection practices of South Asian women: Knowledge, attitudes, and beliefs. *Oncology Nursing Forum* 25, 1693-1701.
- Choudhry, U.K., (1998). Health promotion among immigrant women from India living in Canada. *Image-The Journal of Nursing Scholarship*, 30, 269-274.

- Campbell, J.B. (2002). Breast cancer race, ethnicity, and survival: A literature review. *Breast Cancer Research and Treatment*, 74 (2), 187-192.
- Department of Health and Human Services. (2000). Healthy people 2010: Understanding and improving health. Retrieved November 16, 2006, from <http://www.healthypeople.gov/Documents/HTML/Volume1/03Cancer.htm>
- Gagliano, M, E. (1988) A literature review on the efficacy of video in patient education. *Journal of Medical Education*, 63, 785-792.
- Hoare, T. (1996). Breast screening and ethnic minorities. *British Journal of Cancer. (Suppl. 29)*, S38-S41.
- Hoare, T., Thomas, C., Biggs, A., Booth, M., Bradley, S. & Friedman, E. (1994). Can the uptake of breast screening by Asian women be increased? A Randomized controlled trial of a linkworker intervention (see comments). *Journal of Public Health Medicine*, 16(2), 179-185.
- Islam, N., Kwon, S.C., Senie, R., & Kathuria, N. (2006). Breast and cervical cancer screening among South Asian women in New York City. *Journal of Immigrant and Minority Health*, 8(3), 211-221.
- Israel, B., Schuls, A.J., Parker, E.A., & Becker, A.B. (1998). Review of community-based research: Assessing partnership approaches to improve health. *Annual review of public health*, 19, 173-202.
- Kamath, S., Murillo, G., Chatterton, R., Hussain, E., Amin, D., Mortillaro, E., Peterson, C. & Alekel, D. (1999). Breast cancer risk factors in two distinct ethnic groups: Indian and Pakistani vs. American premenopausal women. *Nutrition and Cancer*, 35(1), 16-26.
- Kernohan, E. E. (1996). Evaluation of a pilot study for breast and cervical cancer Screening with Bradford's minority ethnic women; a community Development approach. 1991-93. *British Journal of Cancer. (Suppl.29)*, S42-S46.
- Kim, K., Yu, E, S., & Chen, E.H. (1998). Breast cancer screening knowledge and practices among Korean American women. *Asian American Pacific Islander Journal of Health*, 6(2), 263-275.
- Kumar, E. E., Genevieve, P. Z., & Simpkins, S. (2009) Identifying factors that influence breast cancer screening practices in South Asian Indian immigrant women. Presentation at American Public Health Association. Philadelphia.

- Kwong, S. (2204). Cancer statistics for California's Asian Americans. Proceedings of the 5th AANCART Asian American Cancer Control Academy, CA: Sacramento.
- Lovejoy, N.C., Jenkins, C., Wu, T., Shankland, S., & Wilson, C. (1989) Developing a breast cancer screening program for Chinese-American women. *Oncology Nursing forum*, 16, 181-187.
- Maxwell, C.J., Kozak, J.F., Desjardins-Denault, S.D., & Parboosingh, J. (1997). Factors important in promoting mammography screening among Canadian women. *Canadian Journal of Public Health*, 88, 346-350.
- Maxwell, C.J., Bancej, C.M., & Snider, J. (2001). Predictors of mammography use among Canadian women aged 50-69: Findings from the 1966/97 National Population Health Survey. *Canadian Medical Association Journal*, 164, 329-334.
- McCance, K., Mooney, K., Smith, K., & Field, R. (1990). Validity and reliability of a breast cancer knowledge test. *American Journal of public Health*, 77(12), 1515-1517.
- Mcade, C.D., McKinney, W.P., Barnas, G.P. (1994) Education patients with limited literacy skills: the effectiveness of printed and videotaped materials about colon cancer. *American Journal of Public health*, 1994;84:119-21.
- McCance, K., Mooney, K., Smith, K., & Field, R. (1990). Validity and reliability of a breast cancer knowledge test. *American Journal of public Health*, 77(12), 1515-1517.
- Olsen, L.M., Reis, J., Murphy, L., & Gehm, J.H. (1988). The religious community as a partner in health care. *Journal of Community Health*, 13(4), 249-257.
- Parkin, D.M., Muir, C. S. (1992). Cancer incidence in five continents. Comparability and quality of data. *IARC Science Publications*, 120, 45-173.
- Parkin, D., Whelan, S., Ferlay, J., Raymond, L., & Young, J. (1997). Cancer Incidence in five continents, VII.
- Partridge, M,R. (1986). Asthma education:more reading or more viewing? *Journal Review of Social Medicine*, 79, 326-328.
- Powe, B.D. (1995a). Cancer fatalism among elderly Caucasians and African Americans. *Oncology Nursing Forum*, 22(9), 1355-1359.

- Powe B.D. (1995b). Fatalism among elderly African Americans: Effects on colorectal cancer screening. *Cancer Nursing*, 18(5), 385-392.
- Prochaska, J.O., Redding, C. A., & Evers, K.E. (1997). The transtheoretical model and stages of change. *Health Behavior and Health Education: Theory, Research, and Practice* (second ed.). San Francisco, CA: Jossey-Bass Publishers.
- Qureshi, M., Thaker, H.L., Litaker, D.G., & Kippes, C. (2000). Differences in breast cancer screening rates: An issue of ethnicity or socioeconomic? *Journal of Women's Health and Gender-based Medicine*, 9 (9), 1025-1031.
- Rawl, S. M., Champion, V.L., Menon, U., & Foster, J.L. (2000). Vietnamese American women: Breast cancer knowledge, attitudes, and screening adherence. *American Journal of Health Promotion*, 15 (4), 357-363.
- Stone, S., Holden, A., Knapie, N., Ansell, J. (1989). Comparison between videotape and personalized patient education for anti-coagulant therapy. *Journal of Family Practice*, 29, 55-57.
- Swan, J., Breen, N., Coates, R.J., Rimer, B.K., & Lee, N.C. (2003). Progress in cancer screening practices in the United States: Results from the 2000 National Health Interview Survey, *Cancer*, 97(6), 1528-1540.
- Sarna, L., Tae, Y.S., & Kim, Y.H. (2001). Cancer screening among Korean Americans. *Cancer Practice*, 9(3), 134-140.
- Sutton, G.C., Storer, A., & Rowe, K. (2001). Cancer screening coverage of South Asian women in Wakefield. *Journal of Medical Screen*, 8(4), 183-186.
- Strecher, V.J. & Rosenstock, I.M. (1997). Health belief model. . *Health Behavior and Health Education: Theory, Research, and Practice* second ed.). San Francisco, CA: Jossey- Bass Publishers.
- Tanjasiri, S. P., & Santos, S. L. (2001). Breast cancer screening among Chamorro women in southern California. *Journal of Womens Health Gender Based Medicine*, 10(5), 479-485.
- U. S. Census Bureau. (2000). Current Population Survey. US Bureau of the Census.

Winter, H., Cheng, K. K., & Cummins, C. (1999). Cancer incidence in the South Asian population of England (1990-1992). *British Journal of Cancer*, 79 (3-4), 645-654.

Wood, R.Y. (1996). Breast Self-Examination Proficiency in Older Women: Measuring the Efficacy of Video Self-Instruction Kits. *Cancer Nursing*, 19:429-436.

APPENDIX A

Definitions

Knowledge of breast cancer: the information and understanding of breast cancer gained from experience, values, attitudes, beliefs, and educational programs.

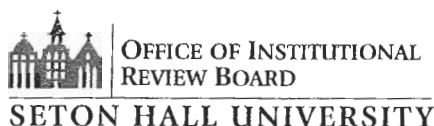
(Green, Kreuter, Deeds, & Partridge, 1980; Merriam Webster's Collegiate Dictionary, 1994; Weinrich et al., 1992).

Cancer fatalism: the belief that death is inevitable when cancer is present as measured by the Powe Fatalism Inventory. (Powe, 1995a).

Cultural sensitivity: is defined conceptually, in its broadest sense, as "the extent to which ethnic/cultural characteristics, experiences, values, and beliefs of a target population are incorporated into the design, delivery, and evaluation of targeted health promotion materials and programs" (Resnicow, Baronowski, Ahluwalia, & Braithwaite, 1998).

Culture: is used because it implies the integrated patterns of human behavior that include language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social group.

APPENDIX B- IRB APPROVAL



December 16, 2008

Elise Elizabeth Kumar
4 Country Club Lane
Florham Park, NJ 07932

Dear Ms. Kumar,

The Seton Hall University Institutional Review Board has reviewed the information you have submitted addressing the concerns for your proposal entitled "The Effects of Culturally Sensitive Education in Driving South Asian Indian Women Immigrant Women towards Mammography Screening in New Jersey". Your research protocol is hereby approved as revised through expedited review. The IRB reserves the right to recall the proposal at any time for full review.

Enclosed for your records are the signed Request for Approval form, the stamped Recruitment Flyer, and the stamped original Consent Form. Make copies only of these stamped forms.

The Institutional Review Board approval of your research is valid for a one-year period from the date of this letter. During this time, any changes to the research protocol must be reviewed and approved by the IRB prior to their implementation.

According to federal regulations, continuing review of already approved research is mandated to take place at least 12 months after this initial approval. You will receive communication from the IRB Office for this several months before the anniversary date of your initial approval.

Thank you for your cooperation.

In harmony with federal regulations, none of the investigators or research staff involved in the study took part in the final decision.

Sincerely,

Mary F. Ruzicka, Ph.D.
Mary F. Ruzicka, Ph.D.
Professor
Director, Institutional Review Board

cc: Dr. Genevieve Pinto Zipp

Presidents Hall • 400 South Orange Avenue • South Orange, New Jersey 07079-2641 • Tel: 973.313.6314 • Fax: 973.275.2361

A HOME FOR THE MIND, THE HEART AND THE SPIRIT


**REQUEST FOR APPROVAL OF RESEARCH, DEMONSTRATION OR
RELATED ACTIVITIES INVOLVING HUMAN SUBJECTS**

All material must be typed.

PROJECT TITLE: The Effects of Culturally Sensitive Education in Driving South Asian Indian Immigrant Women Towards Mammography Screening in New Jersey

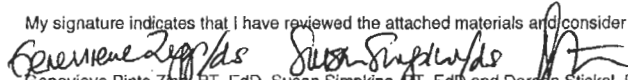
CERTIFICATION STATEMENT:

In making **this application**, I(we) certify that I(we) have read and understand the University's policies and procedures governing research, development, and related activities involving human subjects. I (we) shall comply with the letter and spirit of those policies. I(we) further acknowledge my(our) obligation to (1) obtain written approval of significant deviations from the originally-approved protocol BEFORE making those deviations, and (2) report immediately all adverse effects of the study on the subjects to the Director of the Institutional Review Board, Seton Hall University, South Orange, NJ 07079.


Elise Elizabeth Kumar 9/1/08
RESEARCHER(S) OR PROJECT DIRECTOR(S) DATE

**Please print or type out names of all researchers below signature.
Use separate sheet of paper, if necessary.**

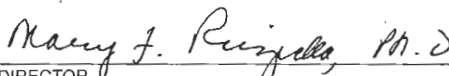
My signature indicates that I have reviewed the attached materials and consider them to meet IRB standards.


Genevieve Pinto Zito, PT, EdD, Susan Simpkins, PT, EdD and Doreen Stiskal, PT, PhD 9/1/08
RESEARCHER'S ADVISOR OR DEPARTMENTAL SUPERVISOR 11/3/08 DATE

Please print or type out name below signature

The request for approval submitted by the above researcher(s) was considered by the IRB for Research Involving Human Subjects Research ~~at the~~ in Nov. 2008 ~~meeting.~~

The application was approved not approved by the Committee. Special conditions were were not set by the IRB. (Any special conditions are described on the reverse side.)


Mary J. Ruizella, Ph.D. 12/16/08
DIRECTOR, DATE
SETON HALL UNIVERSITY INSTITUTIONAL
REVIEW BOARD FOR HUMAN SUBJECTS RESEARCH

APPENDIX C- FLYER



STUDY PARTICIPANTS NEEDED!



Your participation is needed in a research study. The results will assist nurses and physicians involved in breast cancer research and treatment. It will give these health professionals a better understanding of what women know about breast cancer and their intention to seek mammograms.

Are you a South Asian Indian Immigrant Woman, age 40+, residing in New Jersey?

If so, you are eligible to participate. The study consists of three short questionnaires that will be filled out by you. The entire study will take no more than 40 minutes of your time.

Your participation is very important.

Please contact me at:
ELISE ELIZABETH KUMAR
 Doctoral Student
 Seton Hall University
 (973) 214-5111
 Email: kumareli@shu.edu
 Thank you!

Seton Hall University
 Institutional Review Board

DEC 16 2008

Approval Date

Expiration Date

DEC 16 2009

APPENDIX D- SCREENING TOOL

Checklist

ID _____

Appointment Date for Data Collection _____

	YES	NO
To participate in this study You must be above 40 years old	-----	-----
Born in South Asia (India)	-----	-----
No history of breast cancer	-----	-----
Mammogram not within 12 months	-----	-----
Understand English (speak) (able to carry on short conversation)	-----	-----
Read and write in English	-----	-----

APPENDIX E- INFORMED CONSENT FORM**SETON HALL UNIVERSITY****Consent to Participate in a Research Study****Title of Research Study:**

"The Effects of Culturally-Sensitive Education in Driving South Asian Indian Immigrant Women towards Mammography Screening in New Jersey"

Principal Investigator:

Elise E. Kumar, M.Sc, M.S., MPH
 Doctoral Student
 Seton Hall University
 Graduate Program of Health Sciences
 South Orange, New Jersey

Seton Hall University
 Institutional Review Board

DEC 16 2008

Approval Date

Expiration Date

DEC 16 2009

Purpose of the Study:

Participants have been asked to participate in a study which looks at the effects of culturally-sensitive educational materials in influencing South Asian Indian Immigrant women to seek mammogram screenings. The information collected from the participants will lead to a better understanding of what women know about breast cancer and mammography. Participants will be shown a video or given a brochure and will be asked to complete a total of three questionnaires. The entire study will take no more than 40 minutes of their time.

The main benefit from their participation in this study will provide health professionals with insight on how to design the best breast cancer educational programs tailored to meet the needs of South Asian Indian population group, who will then get information on topics such as breast self-examination or where to have mammograms provided at no cost.

Study Information:

If participants agree to participate in the study, they will be asked to come.

When participants arrive, they will be asked to answer some factual questions about themselves, including information about their age, marital status and occupation. After participants complete the questionnaires, they will be shown a video or given a brochure. At the end of the video or brochure, they will be asked to complete three questionnaires.

First, participants will be asked to answer eighteen (18) questions about breast cancer and their knowledge about this disease. This questionnaire is called the Breast Cancer Knowledge Test (BCKT) and consists of both true/false and multiple choice questions. Participants will also be asked to fill out a second questionnaire with fifteen (15) questions about their feelings on cancer; it is called the Powe Cancer Fatalism Test (PCFT). The questions can be answered with a "yes" or "no." Lastly, participants will be asked to complete the Screening Intention (Valdez) Test, which consists of three (3) "yes" or "no" questions about their intention to seek information about breast cancer screening. Three months after this session, the Screening Intention questionnaire will be mailed out to find out if participants have scheduled a mammogram or have sought information about breast cancer.

School of Health and Medical Sciences
 Department of Graduate Programs in Health Sciences
 Tel: 973.275.2076 • Fax: 973.275.2171
 400 South Orange Avenue • South Orange, New Jersey 07079 • shms.shu.edu

SETON HALL UNIVERSITY

Participation in this research study is entirely voluntary. If participants choose not to participate, they may withdraw at any time.

The study will be completely anonymous and confidential. Participants' name and any identifying information, such as their social security number, will not be collected; they will be issued a study identification number. Any information that is collected will be securely stored and kept in a locked cabinet at the principal investigator's home. The principal investigator will be the only person to have access to the data.

Risks:

Potential risks associated with participation in this study might include:

1. Anxiety due to fear of discontinuation of services at the temple for participation or non-participation in the study
2. Anxiety or emotional responses due to the sensitive nature of some of the questions
3. Loss of time related to participation in the study

Financial Compensation:

Participants will not be paid to participate in this study.

Compensation for Injury:

There are no physical risks associated with study participation. Should participants receive an injury while participating in the study, no compensation will be provided.

Contact Information:

If you have any questions about the study, please contact:
 Elise Kumar OR Dr. Genevieve Zipp
 kumareli@shu.edu zippgene@shu.edu
 Seton Hall University
 Graduate Medical Education Department
 South Orange, New Jersey.

Approval of the Institutional Review Board:

This project has been reviewed and approved by the Seton Hall University Institutional Review Board for Human Subjects Research. The IRB believes that the research procedures adequately safeguard the subject's privacy, welfare, civil liberties, and rights. The Chairperson of the IRB may be reached at 973-313-6314.

By signing below participants are agreeing to participate in this research study.

Signature of Subject

Date

Expiration Date
DEC 16 2009

Please sign and return one copy of the above consent form. The other copy is for you to keep. Thank you. Seton Hall University
Institutional Review Board

School of Health and Medical Sciences
 Department of Graduate Programs in Health Sciences
 Tel: 973.275.2076 • Fax: 973.275.2171
 400 South Orange Avenue • South Orange, New Jersey 07079 • shms.shu.edu

DEC 16 2008

Approval Date

APPENDIX F-SURVEY

PART I-DEMOGRAPHICS

Note: For all of the questions below please check, circle or write your response

1) Where were you born?

India _____

Pakistan _____

SriLanka _____

Nepal _____

Bangladesh _____

2) What is your age? _____

3) At what age, did you move to the United States? _____

4) How long have you been in the U.S.A?

Less 1 yr 2-3 yrs 4-6 yrs 7-9 yrs 10+ yrs

5) Marital Status:

Single _____

Married _____

Divorce _____

Widow _____

6) How many years of schooling have you completed?

Elementary _____

Middle school _____

High school _____

College _____

Graduated from college _____

Graduate school/professional degree _____

7) What is your current employment status?

Full-time _____

Part-time _____

Not employed _____

PART II

- 1) Have you ever heard of a mammogram? Yes No
- 2) Do you know what a mammogram is? Yes No
- 3) Can women get cancer in the breast? Yes No
- 4) Why do women have mammograms? ***Check all that apply***
- Too check for lumps _____ Check for cancer _____
- As part of physical exam _____ Doctors orders _____
- Family history _____ Other _____
- 5) Have you ever had a mammogram?
 If YES, when was your last one?
- Less than 2 years ago, 2-3 yrs ago 3+ yrs
- 6) Do you have health insurance coverage? Yes No
- 7) If YES, What kind of insurance coverage?
- Medicare _____
- Medicaid _____
- Health Insurance (work) _____
- Health Insurance (private) _____
- Other _____
- 8) Do you have a Primary Care Physician?
- No _____
- Yes _____
- 9) What is the gender of your Primary Care Physician?
- Male _____
- Female _____
- 10) Do you prefer to see a female health care provider for a mammogram?
- No _____
- Yes _____

11) Do you know anyone who had breast cancer?

Yes _____

No _____

12) Has anyone in your family had breast cancer?

Yes _____

No _____

13) Do you think you may someday get breast cancer?

Yes _____

No _____

14) Do you think it is important for women to check their own breasts for lumps?

Yes _____

No _____

Thank you for participating.

APPENDIX G- BREAST CANCER KNOWLEDGE TEST (QUESTIONNAIRE -1)

ID # _____

There are 18 Questions. Please circle your answer for each question. It is important to this research that you complete this survey from your own knowledge, without help from any other source(either person or written material).

- 1) If you are post-menopausal, how often should you do breast self-examination:
 - a) each week
 - b) once a month
 - c) every three months

- 2) Most breast lumps are found by:
 - a) women themselves
 - b) physician
 - c) mammogram

- 3) How much difference does regular breast cancer screening make in the chance of curing breast cancer:
 - a) a great deal
 - b) some difference
 - c) little or no difference

- 4) A woman who regularly feels her breasts is doing one of the most effective methods of breast cancer detection
 - a) True
 - b) False

- 5) Mammography can detect lumps that can't be felt by hand.
 - a) True
 - b) False

- 6) At what age should a young woman begin doing breast self-examination? (BSE):
 - a) 20
 - b) 30
 - c) 35

- 7) If a woman gets regular mammography, she does not need to do breast self examination (BSE) or have physical examinations
 - a) True
 - b) False

- 8) Mammography is recommended yearly for women over 40 years old.
 - a) True
 - b) False

- 9) Using the palm of your hand is the most effective method for detecting a breast lump
 - a) True
 - b) False
- 10) Breast self-examination (BSE) should be performed during your menstrual period when lumps are most easily detected
 - a) True
 - b) False
- 11) An important part of breast self-examination (BSE) is looking at your breast in the mirror
 - a) True
 - b) False
- 12) It is not necessary to look at your breasts during breast self-examination (BSE)
 - a) True
 - b) False
- 13) Some nipple discharge is expected as you get older when you squeeze the nipple during breast self-examination (BSE)
 - a) True
 - b) False
- 14) Breast self-examination (BSE) should include feeling for lumps under your arm
 - a) True
 - b) False
- 15) Squeezing the nipple is necessary for a good examination
 - a) True
 - b) False
- 16) How often should breast self-examination (BSE) be performed?
 - a) Every 6 months
 - b) Once a month
 - c) Once a week
- 17) When feeling (palpating) the breast, you should:
 - a) Use the pads of your fingers
 - b) Use the tips of our fingers
 - c) Don't know
- 18) Abnormal breast change includes the following:
 - a) Discharge
 - b) Lump, hard knot, or thickening
 - c) Dimpling of the skin

APPENDIX H- POWE FATALISM (QUESTIONNAIRE -2)

Directions: Please answer the following questions based on what you think. Remember that there is no right or wrong answers. Whatever you think is the right answer.

1. I believe if someone is meant to have cancer, it doesn't matter what they eat, they will get cancer anyway.	YES	NO
2. I believe if someone has cancer, it is already too late to do anything about it.	YES	NO
3. I believe someone can smoke all their life, and if they are not meant to get cancer, they won't get it.	YES	NO
4. I believe if someone is meant to get cancer, they will get it no matter what they do.	YES	NO
5. I believe if someone gets cancer, it was meant to be.	YES	NO
6. I believe if someone gets cancer, their time to die is near.	YES	NO
7. I believe if someone gets cancer, that's the way they were meant to die.	YES	NO
8. I believe getting checked for cancer makes people think about dying.	YES	NO
9. I believe if someone is meant to have cancer, they will have cancer.	YES	NO
10. I believe some people don't want to know if they have cancer because they don't want to know they may be dying from it.	YES	NO
11. I believe if someone gets cancer, it doesn't matter when they find out about it, they will still die from it.	YES	NO
12. I believe if someone gets cancer a lot of different treatments won't make any difference.	YES	NO
13. I believe if someone was meant to have cancer, it doesn't matter what the doctor tells them to do, they will get cancer anyway.	YES	NO
14. I believe if someone is meant to have cancer, it doesn't matter if they eat healthy foods, they will still get cancer.	YES	NO
15. I believe cancer will kills most people who get it.	YES	NO

APPENDIX I- SCREENING INTENTIONS

Directions: Please circle your answer to the following questions.

1) Do you have intention to seek information about breast cancer?

Yes

No

2) Do you have intention to ask your physician about a Mammogram referral?

Yes

No

3) Do you intend to obtain a mammogram in the near future (within 3 months)?

Yes

No

**APPENDIX J- FOLLOW UP SCREENING PARTICIPATION/INTENTION
QUESTIONS**

Directions: Please circle your answer to the following questions.

1) Would you continue to have intention to seek information about breast cancer?

Yes

No

2) Would you continue to have intention to ask your physician about a mammogram referral?

Yes

No

3) Would you continue to obtain a mammogram in the near future?

Yes

No

4) Did you seek mammography service within the three months after the study?

Yes

No

APPENDIX K- PERMISSION TO ADAPT THE INSTRUMENT BY AUTHOR

KATHY McCANCE

-----Original Message-----

From: Kathy.McCance@nurs.utah.edu
To: franklinkumar@aol.com
Sent: Mon, 4 Dec 2006 6:50 PM
Subject: RE: permission to use the Breast Cancer knowledge test

Hello---I am sorry for the delay on this I have been traveling---and yes you have my permission---Thanks---
Kathy mccance

-----Original Message-----

From: franklinkumar@aol.com [<mailto:franklinkumar@aol.com>]
Sent: Mon 12/4/2006 12:51 PM
To: Kathy McCance
Cc: kumareli@shu.edu
Subject: permission to use the Breast Cancer knowledge test

Dear Dr. McCance,
As per the message you left on the phone regarding the permission to use the Breast Cancer Knowledge Test, I sincerely thank you for that. My research proposal focuses on the effectiveness of a culturally sensitive cancer education program on knowledge of breast cancer, fatalism, and screening intention among South Asian women. I still need your written permission to use the scale. I look forward to receiving a written permission from you to this email address: kumareli@shu.edu

Sincerely,
Elise Kumar
Seton Hall University

APPENDIX L- PERMISSION TO ADAPT THE INSTRUMENT BY AUTHOR POWE

From: Barbara.Powe@cancer.org

To: franklinkumar@aol.com

Cc: bpowe@cancer.org, Franklinkumar@aol.com, kumareli@shu.edu

Date: Wednesday, November 08, 2006 09:13AM

Subject: Re: Permission to use Powe's Inventory Scale

Ms. Kumar,

Thank you for your interest in the PFI and I look forward to hearing the results of your study.

(See attached file: Powe Fatalism Inventory.doc)

Powe, B.D. (1995). Cancer fatalism among elderly Caucasian and African Americans. *Oncology Nursing Forum*, 22(9), 1355-1359.

Powe, B.D., Daniels, E., & Finnie, R. (2005). Comparing Perceptions of Cancer Fatalism among African Americans Patients and Their Providers

Journal of the American Academy of Nurse Practitioners, 17(8), 318-32

Barbara D. Powe, PhD, RN
Director, Underserved Populations Research
Behavioral Research Center
American Cancer Society
1599 Clifton Road
Atlanta, GA 30329
Phone: 404-329-7749
Cell: 404-798-6910
Fax: 404-929-6832

APPENDIX M- PERMISSION TO ADAPT THE INSTRUMENT BY AUTHOR

VALDEZ

From: avaldez@healthpointcommunications.com
To: kumareli@shu.edu
Date: Thursday, August 21, 2008 11:13AM
Subject: Re: Permission to use Screening Intention Questions

Dear Elise,
It's nice to hear from you and learn that you are making progress on your doctoral studies.
I'm encouraged by your request to use my screening intentions questions in your study
and herein grant permission to use my screening intentions scale.

Wishing you the very best in your research,
Armando

Armando Valdez, Ph.D.
President & CEO
HealthPoint Communications
201 San Antonio Circle, Suite 152
Mountain View, CA 94040-1234
(650) 917-6600 phone
(650) 917-6601 fax
avaldez@healthpointcommunications.com

APPENDIX N- APPROVAL TO USE VIDEO FROM NJCEED

From:
Martha Lehlbach, MA, RNCS
Project Director of Cancer Screening
Box 18, Morristown Memorial Hospital
100 Madison Ave, Morristown, NJ-07962

To:
Ms. Elise Elizabeth Kumar, M.Sc. M.S.
Doctoral Candidate
Graduate School of Medical Science
Seton Hall University,
400 South Orange Avenue, NJ-07079

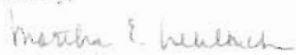
August 05, 2008

Dear Ms. Kumar,

I grant you permission to use the CD by NJCEED that is culturally sensitive for South Asian Indian Women in your dissertation research, which focuses on the effectiveness of a culturally sensitive cancer education program on fatalism, knowledge of breast cancer, and their intention in participation in mammography screening among South Asian Indian Women.

Congratulations on your accomplishments.

Sincerely,


Martha Lehlbach, MA, RNCS

APPENDIX O- CONTACT LIST**CONTACT LIST FOR FREE MAMMOGRAM SCREENING****Morristown Memorial Hospital**

100 Madison Ave,
Morristown, NJ 07962
Phone: (973) 971-5952
Martha Lehlbach

Saint Clare's Hospital

25 Pocono Road,
Denville, NJ 07834
Phone: (973) 983-5720
Cynthia Lyons

Zufall Health Center

19 S. Warren Street
Dover, NJ 07801
Phone: (973) 328-3344
Dorothy Den Bleyker

Planned Parenthood of Northern NJ

30 North Morris Street
Dover, NJ 07801
Phone: (973) 361-6006
Kathy Solomon