

REASONS WHY LOW-INCOME WOMEN IN NORTHWEST MISSOURI
DO NOT ACCESS NO-COST MAMMOGRAPHY SERVICES

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REASONS WHY LOW-INCOME WOMEN IN NORTHWEST MISSOURI
DO NOT ACCESS NO-COST MAMMOGRAPHY SERVICES

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University of Missouri-Kansas City, 2010

ABSTRACT

Mammography is one of the best screening methods to detect early breast cancer, identify the cancer at a more treatable stage, expand treatment options, and reduce mortality. Despite access to no-cost mammography services, Missouri women experience the lowest mammography utilization rate in the nation. In Northwest Missouri the rate of mammography utilization is particularly low: 1 in 3 women over the age of 40 years have never had a mammogram. The purpose of this study was to identify factors that prevent uninsured, low-income women from Northwest Missouri from accessing no-cost mammography services. A narrative descriptive design was utilized to: 1) examine attitudes concerning mammography, 2) gain insight into perceived barriers and facilitators to mammography, 3) gain an understanding of factors influencing mammography behavior and 4) identify potential strategies to increase mammography access and utilization among uninsured, low-income women age 40 to 64

years in Northwest Missouri who have never had a mammogram. Participants in this study (n=12) were recruited from community agencies that provided social services to low-income families. Semi-structured individual interviews were conducted, guided by the Integrated Behavioral Model. Data were analyzed using content analysis to formulate narrative descriptions about attitudes, perceived norms, perceived control, and self-efficacy concerning mammography use. There were four themes that emerged from the data: Competing priorities, the costs of having a ‘free’ mammogram, attitudes about mammography, and navigating the ‘red tape’. Findings indicated that the participants in this study experienced competing priorities and viewed screening behaviors, such as mammography, as a low priority. These women had conflicting attitudes about the advantages and disadvantages of mammography. Their perceptions about mammography were greatly influenced by family and friends. The overarching barrier to no-cost mammography for each of the participants was the amount of “red tape” encountered when navigating the healthcare system in order to obtain a “free” mammogram. Findings from this study may serve to inform future intervention strategies that may reduce barriers and increase utilization of no-cost mammography programs by eligible women.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Nursing, have examined a dissertation titled *Reasons Why Low-Income Women in Northwest Missouri Do Not Access No-Cost Mammography*, presented by Crystal R. Harris, candidate for the Doctor of Philosophy degree, and hereby certify that in their opinion it is worthy of acceptance.

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DEDICATION

To my sons, Reece and Joe

and

To my daughter, Bailey

CHAPTER 1

INTRODUCTION

Disparities exist in the detection and prognosis of breast cancer for uninsured, low-income American women (Byers et al., 2008). Uninsured women have a higher prevalence of more severe, later stage breast cancer (American Cancer Society [ACS], 2007b). Mammography is a screening tool that can identify breast cancer at an earlier stage and improve cancer related outcomes (Smith, Cokkinides, & Brawley, 2008). However, uninsured women do not typically utilize mammography services resulting in the diagnosis of breast cancer at a later stage (ACS, 2007a, ACS, 2007b, Blanchard et al., 2004). Despite a number of interventions to improve mammography access, underutilization of mammography among low-income, uninsured women remains a serious problem resulting in a higher mortality rate due to breast cancer (Centers for Disease Control [CDC], 2006b; Edwards et al., 2008; Ekwueme et al., 2008; McAlearney, Reeves, Tatum, & Paskett, 2007; Meissner, Breen, Taubman, Vernon, & Graubard, 2007; Sabatino et al., 2008; Skinner et al., 2007; Sohl & Moyer, 2007; Taylor et al., 1999).

Healthy People 2010 set the utilization goal for mammography at 70% for women 40 years and older (i.e. a mammogram within the last two years) (CDC, 2010). Although there has been some increase in the percentage of women accessing mammography from year to year, the latest data suggests no improvements (See Table 1) (CDC, 2010). Low income status continues to negatively impact utilization of

mammography. Mammography disparities for women living in urban versus rural locations are also evident (see Table 1). Women living in rural or non-metropolitan areas continue to underutilize mammography at a lesser rate than women living in urban areas, despite income status.

Table 1

Healthy People 2010 Objective 03-13: United States women receiving mammography

	Baseline					Goal
	1998	2000	2003	2005	2008	2010
All women	67%	70%	70%	67%	67%	70%
<i>Geographic Location</i>						
Rural	65%	68%	69%	66%	60%	70%
Urban	68%	71%	71%	70%	67%	70%
<i>Income</i>						
Poor	50%	55%	55%	48%	51%	70%
Near Poor	55%	57%	60%	55%	55%	70%
Middle/High	72%	75%	76%	74%	72%	70%

Note: Age-adjusted, aged 40 years and older

Rural-urban continuum code definitions available at the Surveillance Epidemiology and End Results (SEER) definitions: <http://seer.cancer.gov/seerstat/variables/countyattribs/ruralurban.html#about>

An estimated 40% of Missouri women with annual incomes less than \$25,000 have not had a recent mammogram (Missouri Department of Health and Senior Services [MODHSS], 2006). Of the seven geographical areas comprising the state of Missouri, Northwest Missouri (NWMO) has the lowest rate (Appendix A). Approximately 36% of uninsured women over the age of 40 years who reside in NWMO have never had a mammogram and 65.6% have not had a mammogram in the last year (MODHSS, 2007). In 2009, the Komen Foundation of Greater Kansas City conducted a community profile/needs assessment for its 17 county service area in Northeast Kansas and Northwest Missouri. Buchanan County in NWMO was identified as a targeted county for Komen grants and intervention based on its' significantly higher incidence and mortality rates for breast cancer when compared to national and state rates as well as its high number of families living at or below the federal poverty level (Susan G. Komen for the Cure Greater Kansas City Affiliate, 2009). Based on U.S. Census Bureau data, NWMO is described as a single metropolitan statistical area which has a regional hospital that offers a breast center, surrounded by many counties including nonmetropolitan (rural) statistical areas that have local healthcare providers (U.S. Census Bureau, 2006).

Programs such as the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and ENCOREplus, which is a program privately funded by Avon, and the Susan G. Komen Foundation, provide no-cost mammography screening and transportation reimbursement to NWMO. Despite the availability of these no-cost

mammography programs, women residing in NWMO continue to underutilize mammography services (MODHSS, 2010a; Tangka et al., 2006). The NBCCEDP is a federal program initiated in 1991 aimed at improving access to cancer screening for minority and underserved women, yet only 14.7% of all eligible women have received mammography screening (CDC, 2006a; MODHSS, 2010b). Missouri provided mammography for an estimated 5.2% of women eligible for free mammography through the NBCCEDP (Tangka et al., 2006). The Missouri Show-Me-Healthy Women Program that coordinates and administers programs funded by the NBCCEDP reports annual increases in the number screened (MODHSS, n.d.-b). A need existed to better understand why low-income, uninsured women from NWMO were not accessing free healthcare services, such as mammography.

Study Purpose and Specific Aims

The purpose of this qualitative study was to explore the factors influencing mammography utilization among uninsured, low-income NWMO women who qualified for no-cost mammography services. The Integrated Behavioral Model (IBM) was used to guide the elicitation interviews for the purpose of identifying population specific perceptions concerning mammography. The specific aims of this qualitative descriptive study were the following:

1. to explore attitudes concerning mammography;
2. to explore barriers and facilitators to mammography;
3. to gain a better understanding of the factors influencing mammography

utilization; and

4. to identify information that may help to inform strategies to increase mammography access among uninsured, low-income women in NWMO who have never had a mammogram.

Definition of Terms

Integrated Behavioral Model (IBM model) integrates constructs from the theory of reasoned action (TRA)/theory of planned behavior (TPB), social cognitive theory, health belief model and other theories (Fishbein et al., 2001; Montano & Kasprzyk, 2008).

No-cost mammography programs were defined as those mammography services available in Northwest Missouri that are funded through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and ENCOREplus, privately funded by Avon, and the Susan G. Komen Foundation. Services provided include no-cost mammography screening and transportation reimbursement.

Assumptions

Based on the theoretical underpinnings of the Integrated Behavioral Model assumptions were the following:

1. Women need to possess knowledge concerning mammography and how to access services.
2. Women must view mammography as important before they will access mammography services.

3. Environmental constraints such as transportation or geographic location of health care services can prevent mammography behavior.
4. The intention to receive a mammogram is the best predictor of actually receiving one.
5. The intention to obtain a mammogram is directly influenced by a woman's attitudes concerning the advantages and disadvantages of obtaining a mammogram, the importance that significant others place on receiving a mammogram and a woman's perceived ability to obtain a mammogram.

Limitations

Limitations of this qualitative study may be found in the study design, study sample, and data collection methods. These include study population participants who self selected to participate may result in participant-selection bias and these results may not be transferrable to other populations since population characteristics and community access issues may be unique.

Significance

Despite programs to increase access to mammography, low utilization rates continue to exist for low-income, uninsured women (Cui et al., 2007; Sabatino et al., 2008; Smith, Cokkinides, & Brawley, 2008; Tangka et al., 2006). Typically, women are recruited from health care agencies for mammography-related studies; however, the recruitment of women from non-health care agencies is less common. Low-income, uninsured women who have never had a mammogram may have been previously

understudied due to difficulty making initial contact (Paskett et al., 2008; Peek & Han, 2004). While door-to-door recruitment and the use of surveys have been successful for recruiting other similar groups of participants, door-to-door recruitment in largely rural areas is time consuming and likely not cost-effective (Ahmed, Lemkau, Nealeigh, & Mann, 2001; Galen, Kaplan, & Pasick, 2007; Lauver, Settersten, Kane, & Henriques, 2003). A unique aspect of this dissertation study was the approach that was used to recruit low-income, uninsured women who have never accessed mammography. Recruitment outside of health care facilities was used to obtain data from individuals not present in a healthcare facility.

Numerous theories have guided research to explain mammography behavior and improve access to mammography (Pasick & Burke, 2008). No single theory, or combination of theories, have been able to fully explain mammography behavior or the underutilization of mammography (Champion & Skinner, 2003; Champion, Skinner, & Menon, 2005; Lauver, Nabholz, Scott, & Tak, 1997; Steele & Porche, 2005b). An innovative aspect of this dissertation study was the use of the Integrated Behavioral Model (IBM model) to guide data collection and analysis. Other researchers have stressed the critical aspect of understanding the salience of a specific behavior, such as mammography, together with social norms, environmental constraints, and self-efficacy from the perspective of the focus population (Montano & Kasprzyk, 2008; Park, Buist, Tiro, & Taplin, 2008; Tolma, Reininger, Evans, & Ureda, 2006). The IBM model emerged from a theorist workshop organized by the National Institute of Mental Health

to integrate common constructs into one theory. A group of leading theorists examined behavior change and identified eight concepts that influence health behavior. Fishbein (2000) and others (Montano & Kasprzyk, 2008) integrated the concepts into a single model which also includes many constructs that have been used previously in mammography utilization research. The concepts of attitude, perceived norm and personal agency which are in the center of the model are key concepts used to guide this study. The IBM model methodology suggests the use of elicitation interviews for the purpose of identifying population specific perceptions concerning the health behavior being studied in order to develop appropriate targeted interventions. Although the Theory of Planned Behavior/Theory of Reasoned Action and combinations of theories, which are integrated in the IBM model, have been used as theoretical frameworks in mammography behavior research (Champion, 1991; Champion et al., 2005; Pasick & Burke, 2008; Steele & Porche, 2005a; Tolma et al., 2006), no published studies using the most recent form of the IBM model were located.

In a review of literature, Pasick and Burke (2008) presented that many theoretically based interventions have been developed to address barriers to mammography, with the most frequently addressed barrier being cost. Despite providing no-cost mammography, underutilization remains (Tangka et al., 2006). Use of the IBM model provides an opportunity to study many concepts that have successfully predicted intention in health behaviors (Montano & Kasprzyk, 2008). The IBM model proposes

that attitudes, perceived norms, and personal agency are direct determinants on the intention to perform a health behavior such as mammography screening (see Figure 1). Knowledge, skills, environmental constraints, and habits are independent determinants of the health behavior according to the model. The concepts of attitude, perceived norms, and personal agency are central to the model and were the key constructs guiding this study.

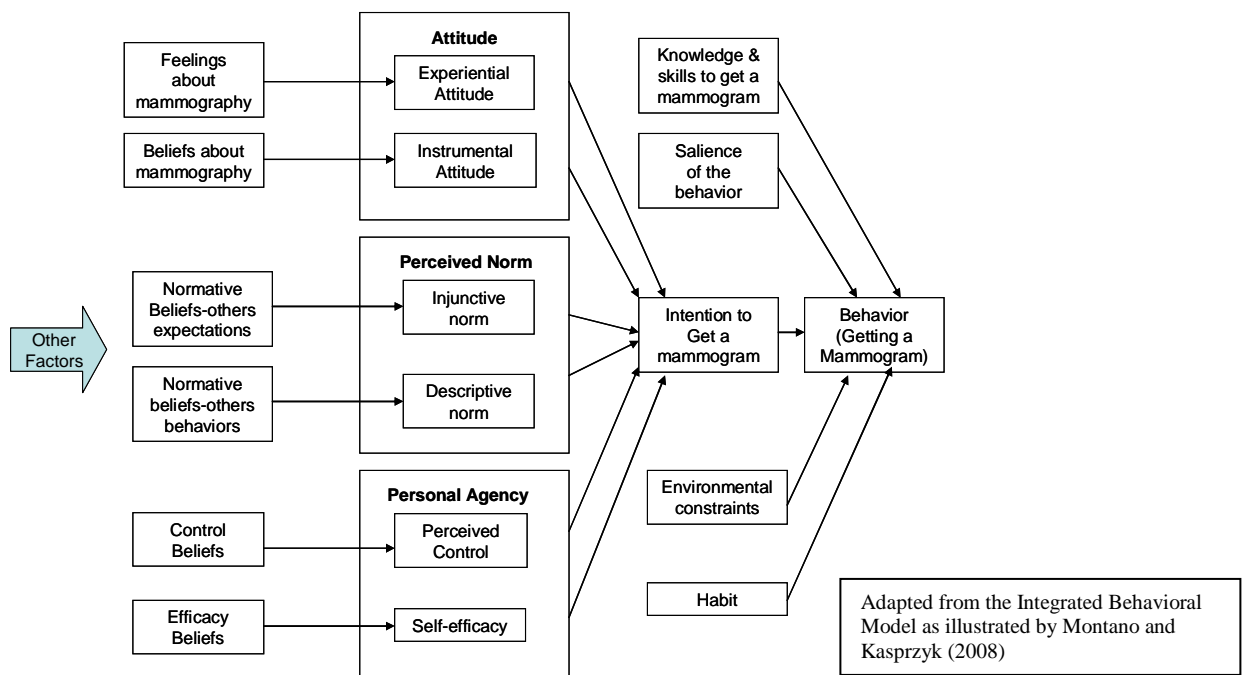


Figure 1. Integrated Behavioral Model and Mammography

This dissertation study targeted a population of uninsured, low-income women who did not have established relationships with health care providers and who had never had a mammogram. Findings of this study provide new insights that can be used by policy makers and community health agencies to increase utilization of mammography, foster early diagnoses and decrease breast cancer morbidity and mortality. Findings from this study can be used to develop interventions to positively impact attitudes and change mammography screening behaviors for low-income, uninsured women in NWMO. In addition, findings may have implications for low-income rural women living in other regions as well.

CHAPTER 2
REVIEW OF LITERATURE

Background

Breast Cancer Disparities and Uninsured Women

Mammography is one of the best screening methods available to detect early breast cancer, identify the cancer at a more treatable stage, expand treatment options and reduce mortality in women (American Cancer Society [ACS], 2008; Meissner et al., 2007; Smith, Cokkinides, & Brawley 2008; Taplin et al., 2004). Women without insurance use mammography approximately 30% less often than insured women (Adams, Breen, & Joski, 2006; Smith, Cokkinides, & Brawley 2008). As a result of decreased screening, uninsured women are diagnosed with two times the number of late-stage breast cancers and have lower survival rates when compared to insured women, irrespective of race (ACS, 2007a; ACS, 2007b). Although Missouri's breast cancer incidence (117.5/100,000) is about the same as the national rate (117.6/100,000), Missouri women experience a significantly higher mortality rate due to breast cancer (25.5/100,000), (National Cancer Institute, 2006).

In Missouri, despite ready availability of no-cost mammography programs, the number of uninsured women accessing such services is low (National Center for Chronic Disease Prevention & Health Promotion, 2006; Susan G. Komen for the Cure Greater Kansas City Affiliate, 2009). Currently, Missouri experiences the lowest mammography utilization rate for uninsured women compared to all other states (ACS, 2007a). In

Northwest Missouri (NWMO), a largely rural, 13 county region, over one in three uninsured women over the age of 40 years have never had a mammogram (Missouri Department of Health and Senior Services, 2007).

Low-income, uninsured women are diagnosed at later stages of breast cancer and experience higher mortality rates when compared to women with Medicaid, Medicare or other insurance (ACS, 2008; Bonfill, Marzo, Pladevall, Marti, & Emparanza, 2001; Chu, Miller, & Springfield, 2007). Uninsured women have lower survival rates despite the stage their cancer was diagnosed (ACS, 2007b). Low-income, low education levels, and living in nonmetropolitan (rural) areas are mediating factors which increased the risk of no insurance, lack of transportation, and lack of access to health care; all associated with decreased breast cancer screening (Coughlin, Leadbetter, Richards, & Sabatino, 2008; Joslyn & West, 2000).

Eliminating health care disparities is one of two key goals established by Healthy People 2010 to best promote and preserve health in the United States (U.S. Dept. of Health and Human Services, 2000). The initiatives of improving access to care and reducing cancer incidence and mortality have been areas of key focus since the Surgeon General's first report, *Healthy People 2000: National Health Promotion and Disease Prevention Objectives* was published in 1979 (Public Health Service, 1979). Critically evaluating national outcomes for mammography allows us to move closer to reducing cancer disparities in the U.S. (Sabatino et al., 2008).

The Importance of Mammography

Women who have early detection of breast cancer by mammography are more likely to be eligible for breast conserving surgery or radiation when compared to cancers that are detected when symptoms appear (ACS, 2010). The ACS currently recommends annual mammography starting at the age of 40-49 years unless risk factors suggest earlier initiation of screening is beneficial (Smith, Cokkinides, & Brawley 2008; Smith, Cokkinides, Brooks, Saslow, & Brawley, 2010). The National Cancer Institute currently recommends mammography screening every one to two years for women 40 years and older (National Cancer Institute, 2009).

In 2009, the United States Preventive Services Task Force (USPSTF) initially recommended against routine screening for women 40 to 49 years and older. The cited rationale was that the benefit of mammography resulted largely among women 50 to 74 years of age; thus, a recommendation (C rating) against routine screening was stated (2009). After public outcry, USPSTF then changed recommendations to state that for women under 50, mammography should be an individual decision based on risks and values (USPSTF, 2010). The ACS came out strongly against the USPSTF's recommendation diminishing the need for mammography among 40 to 49 year old women, stating that annual screening recommendations for women under the age of 50 years has the potential to save greater years of life due to the early detection of breast cancer (Smith, Cokkinides, & Brawley 2010). In addition, screening 1904 women age

40-49 years compared to 1339 for women 50-59 years to save a single life was considered an acceptable difference (Smith, Cokkinides, & Brawley 2010).

Studies support the use of mammography in women age 40 years and older (Armstrong, Moye, Williams, Berlin, & Reynolds, 2007; Badgwell et al., 2008; Nelson et al., 2009). Armstrong et al. (2007) conducted a systematic review of 117 screening mammography studies between 1966 and 2005, which included women aged 40-49 years and found a 7-23% reduction in breast cancer mortality for this group. The mastectomy rate was higher for women receiving mammography; however, the use of chemotherapy and hormone therapy was decreased. Risk of false positive results is also higher in 40-49 year olds (Armstrong et al., 2007).

Badgwell et al. (2008) studied the mammography practices of women 80 years and older. The women diagnosed with breast cancer (n=12,358) were identified from the Surveillance, Epidemiology and End (SEER) Results Medicare database 1996-2002. For each mammogram received, participants reduced their risk of diagnosis with late stage breast cancer 0.37 times. Badgwell et al. (2008) suggested mammography may increase survival from breast cancer, but health status confounded the results since healthier women participated more in screening.

Many have debated the life-saving benefit of mammography screening when compared to risks of radiation exposure, additional testing required due to false positive results, and over-treatment of non-progressing cancer (Armstrong et al., 2007; Baines, 2005; Brewer, Salz & Lillie, 2007; Keen & Keen, 2009; Smith, Cokkinides, & Brawley

2010). However, since the initiation of mammography screening programs, breast cancer mortality has decreased due to the detection of smaller, more treatable cancers (Agency for Healthcare Research and Quality, 2009; Smith, Cokkinides, & Brawley 2010; Tabar, Duffy, Vitak, Hsiu-Hsi Chen, & Prevost, 1999; Tabar, Yen, Vitak, Chen, Smith, & Duffy, 2003). Women's access to mammography is directly impacted by their understandings of current recommendations from high profile organizations (Calvocoressi, Sun, Kasl, Claus, & Jones, 2007). It is important to provide women with information to make an informed decision about mammography (Baines, 2005; Gates, 2001).

The breast cancer 1 and 2 early onset (BRCA-1 and BRCA-2) are genes that suppress abnormal cell growth (cancer). Women who have a BRCA-1 or BRCA-2 mutation, or abnormality, are predisposed to breast cancer and those with first-degree relatives (mothers, aunts, sisters, and daughters) with breast cancer or ovarian cancer are at increased risk (ACS, 2007b). Although options to decrease risk include prophylactic mastectomy, oophorectomy or tamoxifen, approximately half of all women with BRCA-1 or BRCA-2 mutation rely solely on screenings such as mammography or magnetic resonance imaging (MRI) (Metcalf et al., 2008). The ACS encourages women at higher risk for breast cancer due to family history or other factors to discuss breast cancer screening with their primary care provider to determine if mammography or MRI should begin before the age of 40 years (ACS, 2007b).

Genetic predisposition only accounts for less than 5% of breast cancers, which supports the need for breast cancer screening among all women (Steiner, Klubert, & Knutson, 2008). Other non-modifiable risk factors for breast cancer include age and increased estrogen exposure (early menarche and late menopause) (Steiner et al. 2008). Modifiable risk factors include obesity, alcohol use, smoking, and lack of physical activity (Coyle, 2009; Perrier, Caldefie-Chezet, & Vasson, 2009; Steiner et al. 2008). Women of all races diagnosed with breast cancer during routine mammography screenings experience an earlier stage at diagnosis and increased survival at an earlier stage (Armstrong et al., 2007; Badgwell et al., 2008; Jacobellis & Cutter, 2002; Joensuu et al., 2004). Evidence-based reviews have reported that the benefits of mammography outweigh possible risks such as false positive results (Armstrong et al., 2007; Badgwell et al., 2008; Gotzsche & Nielsen, 2006); however, there is continued debate on whether mammography should be done annually or biennially (Smith, Cokkinides, & Brawley 2010; USPSTF, 2009).

Mammography Use

Approximately 36% of uninsured women over the age of 40 years, residing in NWMO have never had a mammogram and 65.6% have not had a mammogram in the last year (MODHSS, 2007). The number of women who have never received a mammography is the highest rate among seven geographical areas comprising the state of Missouri (Appendix A). Although the ACS recommends that all women receive a mammogram annually after the age of 40 years, recent trends indicate a decline in

mammography use (ACS, 2008; Breen et al., 2007). An estimated 40% of Missouri women with annual incomes less than \$25,000 have not had a recent mammogram (MODHSS, 2006).

Programs such as the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and ENCOREplus, privately funded by Avon and the Susan G. Komen Foundation, provide no-cost screening and transportation reimbursement; however, women residing in NWMO continue to underutilize mammography services (Susan G. Komen for the Cure Greater Kansas City Affiliate, 2009; Tangka et al., 2006). The NBCCEDP is a federal program initiated in 1991 to improve access to cancer screening for minority and underserved women, yet only 14.7% of all eligible women have received mammography screening (CDC, 2006a; MODHSS, n.d.-b). Missouri reached an estimated 5.2% of women eligible for free mammography through the NBCCEDP (Tangka et al., 2006). The Missouri Show-Me-Healthy Women Program that coordinates and administers programs funded by the NBCCEDP reports annual increases in the number screened (MODHSS, n.d.-a). Yet underutilization remains a problem (Tangka et al., 2006).

History of the NBCCEDP

The Breast and Cervical Cancer Mortality Prevention Act of 1990 established the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) through the Centers for Disease Control. This program provides breast and cervical cancer screening services to underserved women between 18 and 64 years old who meet income

guidelines (CDC, 2005). Initially, the program only covered the costs of screening services. NBCCEDP provides services through grants and agreements with “state and health departments, tribes and tribal organizations” (p. 1). Grantees (states) are required to match \$1 for every \$3 received. Sixty percent of funds must be used on direct services and the remaining 40% may be used on administrative functions such as program management, public advertising/education, and quality assurance. This program was expanded to broaden the number of women covered under the program to include Native American women through the Indian Health Service in 2001 (CDC, 2005). Provisions have also been made to provide case management and allow Medicaid to cover treatment costs. See Table 2.

Barriers and Facilitators to Mammography Utilization

Women perceive different risks, benefits of, and barriers to obtaining mammography screening dependent upon their stage of adopting mammography (i.e. a continuum of never considered mammography to receiving mammography annually) (Champion, 2003). These perceptions or beliefs concerning mammography correlate with accessing screenings in various populations (Avci & Kurt, 2008; Dundar et al., 2006; Farmer, Reddick, D'Agostino, & Jackson, 2007; Hur, Kim, & Park, 2005). However, these beliefs have only been able to explain part of the reasons why women do access mammography (Champion, Skinner, & Menon, 2005). Table 3 provides a comparison of transtheoretical model (TTM) stages for mammography adoption with associated beliefs among women living in the Midwest (Menon et al., 2007). The

participants of the Menon et al. study include women who participate in an health maintenance organization and those who are being seen in an “indigent clinic”. Race for participants from the clinic are primarily African-American (82.5%).

Table 2

Provisions of the National Breast and Cervical Cancer Early Detection Program

Legislation	Law	Provision
Breast and Cervical Cancer		
Mortality Prevention Act of 1990	PL101-354	Established the NBCCEDP
Women’s Health Research and Prevention Amendments of 1998	PL105-340	Case management added
Breast and Cervical Cancer Prevention and Treatment Act of 2000	PL106-354	Cancer treatment can be provided by Medicaid after diagnosis through NBCCEDP
Native American Breast and Cervical Cancer Treatment of 2001	PL107-121	Indian Health Service may provide access to Medicaid for breast and cervical cancer under the NBCCEDP.

Factors preventing access to mammography screening among low-income women include cost, transportation, physician recommendation, and the perceived ability to overcome such barriers (Champion et al., 2005; McAlearney, Reeves, Tatum, & Paskett et al., 2007; Paskett et al., 2004). In a quantitative literature review (n=195 studies including 4,775,110 women) of factors association with mammography utilization, Schueler, Chu, and Smith-Bindman (2008) identified lack of physician recommendation, lack of primary care provider, and past screening behavior as the strongest predictors for not obtaining a mammography. In addition, these authors identified the percentage of women identifying reasons for not obtaining mammography (See Table 4).

Table 3

Mammography stage of adoption and associated beliefs

Mammography Stage	Definition	Associated beliefs
based on the Transtheoretical Model	(Prochaska, Redding, & Evers, 2002)	(Menon et al., 2007, p. 258)
Precontemplation	Never had a mammogram and not thinking about having one in the next 6 months	Lower perceived self efficacy, benefits of mammography, knowledge and perceived susceptibility

(Table continues)

Table 3

Mammography stage of adoption and associated beliefs (continued)

Precontemplation (continued)		Higher perceived barriers and fatalism when compared to women in contemplation
Contemplation	Never had a mammogram but thinking about having one in the next 6 months	Higher perceived self-efficacy, benefits, fear, knowledge and susceptibility when compared to women in precontemplation.
Action	Had a mammogram within the last 12 months	Had lower perceived barriers than women in the contemplation stage.

Many rural women have identified cost as a barrier to mammography (McAlearney et al., 2007). No-cost screenings, transportation assistance, and screenings on-site funded by the NBCCEDP and ENCOREplus, in theory, should eliminate barriers related to cost although some women may be unaware of the free services (Lyttle &

Stadelman, 2006). Park, Buist, Tiro, and Taplin (2008) has suggested that providing insurance to low-income women is not predictive of mammography access.

Table 4

Reasons for not accessing mammography

Reasons	% of woman
Low income/money concerns	22.0%
Poor healthcare access including lack of knowledge concerning where to obtain exam, transportation problems, location, inconvenience and wait time	19.3%
Time/employer constraints	11.8%
Belief that mammography harmful	13.4%
Belief that mammography is painful	15.3%
Belief that mammogram only needed if symptomatic	27.1%
Belief that mammogram not necessary	20.8%
Embarrassment	11.6%

(Schueler et al., 2008, p. 1489)

Mobile mammography has long been used to facilitate mammography utilization in rural and urban settings for low-income women (Lane, Martin, Uhler, & Workman, 2003; Levin et al., 1997; Skinner, Zerr, & Damson, 1995). Research suggests that mobile

mammography may be more accepted among women who have a primary care provider (Levin et al., 1997; Skinner et al., 1995), younger women who self-refer (Suter & Elmore, 1998), and among some non-white racial groups (Derose, Duan, & Fox, 2002; Levin et al., 1997). Although mobile mammography does not remove all cost and access barriers, it has been found to increase utilization when combined with educational interventions and scheduled in advance at non-public (e.g. shopping center) locations (Lane et al., 2003; Skinner et al., 1995). In addition, mobile mammography has served as a door to the healthcare system for women without previous health care provider relationships.

Lay health advisors and peer educators have been used with some success in reducing perceived barriers, increasing knowledge concerning mammography, and increasing utilization of screening, especially among African American and Hispanic groups (Kobetz, Vatalaro, Moore, & Earp, 2005; Mayo, Sherrill, Crew, Watt, & Mayo, 2004; Paskett et al., 2006). Reminder letters or phone calls have been effective in increasing mammography utilization for select populations (Finney & Iannotti, 2002; Geller et al., 2007). In a systematic review of interventions to increase mammography for low-income women, Bailey et al. (2005) reported that letters and phone calls were not effective. Champion et al. (2007) found a significant increase in mammography rates for women who received tailored letters or phone calls when compared to those receiving usual care in a low-income medical clinic. However, there was no significant change in mammography utilization rates among women who were in the pre-

contemplation stage or had not ever considered mammography. Letters and phone calls require reliable contact information and relationship with a health care provider, which does not exist for many low-income, uninsured women. Specific barriers and perceptions of low-income, underinsured women underutilizing mammography services need to be studied in order to develop community specific interventions (Mobley, Kuo, Driscoll, Clayton, & Anselin, 2008; Russell, Perkins, Zollinger, & Champion, 2006).

The use of theories in mammography access research

A number of theories have been used to explain mammography access research (see Table 5). A review of theory-based research was conducted to identify a guiding theory for this dissertation research. Pasick and Burke (2008) conducted a critical review of theory used in breast cancer screening promotion research. These researchers identified the health belief model (HBM) as most frequently used, and then combinations of theories including the TTM, theory of planned behavior (TPB)/theory of reasoned action (TRA), social cognitive theory (SCT) and PRECEDE-PROCEED model. Many researchers have used one or more of the constructs from these theories and others when studying mammography behavior in various populations (Table 5). Many theorists and researchers have identified a need to examine behavioral theories, looking for concepts that may be the same or similar, as well as to identifying unique concepts within theories that explain behavior. The IBM model emerged from a theorist workshop the National Institute of Mental Health (NIMH) organized to examine behavior change. Theorists who developed SCT, HBM, TRA/TPB, self regulation, self

control, and subjective culture and interpersonal relationships participated in this group (Fishbein et al., 2001). These theorists came to consensus on eight variables that served to determine behavior but were unable to identify a causal model.

Table 5

Selected studies using theory to examine mammography utilization

<i>Authors</i>	<i>Theory/constructs</i>	<i>Comments</i>
Montano & Taplin (1991)	Expanded TRA attitude, affect, subjective norm and facilitating conditions	Worry about cancer is different than the attitude about mammography behavior.
Michels, Taplin, Carter, & Kugler (1995)	TRA and habit	Perceived risk and habit are the best predictors of intention. Few articles identify habit.
Montano, Thompson, Taylor, & Mahloch (1997)	TRA and affect	
Champion & Menon (1997)	Anderson's Theory-Predisposing, enabling and needs	Predisposing, enabling and needs included perceived susceptibility, benefits, barriers which have similar definitions to the HBM constructs
Lauver, Nabholz, Scott, & Tak (1997)	Theory of Care Seeking Behavior (Based on Triandis' work)- Affect-feelings about behavior, utility, beliefs, norms, habit	Anxiety and barriers interacted to influence behavior. Conceptualized facilitators and barriers as two ends of one continuum.
Rakowski et al. (1997)	TTM-pros & cons (decisional balance), stage of adoption	Pros and cons were identified as separate constructs. Suggested barriers or cons were more situation specific than pros which showed less variability
Drossaert, Boer, & Seydel (2003)	TPB; Initiating vs. maintenance of mammography	Constructs are more related to initiation rather than maintenance of mammography behavior

(Table continues)

Table 5 (Continued)

Selected studies using theory to examine mammography utilization

<i>Authors</i>	<i>Theory/constructs</i>	<i>Comments</i>
Tiro et al. (2005)	TTM-pros and cons; SCT-outcome expectations; cancer worries and subjective norms	In instrument validation, cancer worries and cons loaded on the same factor. Outcome expectations similar to pros/cons
Rauscher, Hawley, & Earp (2005)	TTM and attitudes concerning mammography	Different stages of adoption for mammography are associated with different attitudes
Gullatte (2006)	TRA/TPB, spirituality, religiosity	Including spirituality & religiosity with the TRA/TPB allowed for culturally appropriate model for African American populations
Russell, Champion, & Skinner (2006)	HBM-Susceptibility, benefits and barriers; Cultural Assessment Model-personal space, temporal orientation, personal control and fatalism	External control and fatalism significantly different for women with lower when compared to higher income
Otero-Sabogal, Steward, Shema., & Pasick (2006)	TTM	When controlling for income levels, decisional balance associated with TTM stage in five (Filipino, Latino, African-American, Chinese and White) groups
Menon et al. (2007)	HBM and TTM	Changes in beliefs predicted movement in stages of change
Lopez-McKee, McNeill, Bader, & Morales (2008)	TPB/TRA	Suggested TPB, which included spirituality and religiosity, was promising in minority populations
O'Neill et al. (2008)	TPB	Barriers, rather than attitude, better predictor of intention

Fishbein (2000) integrated the constructs into a single model that has been used in 50 countries to study changing health behaviors (Fishbein & Cappella, 2006; Fishbein et al., 2001; Montano & Kasprzyk, 2008). The IBM model (see Figure 1 on p.9) has evolved through a series of studies involving colorectal cancer screening (Montano, Selby, Somkin, Bhat, & Nadel, 2004), HIV prevention (Kasprzyk & Montano, 1998), and mammography (Montano & Taplin, 1991). The IBM model proposes that attitudes, perceived norms, and personal agency are direct determinants on the intention to perform a health behavior such as mammography screening. Knowledge, skills, environmental constraints, and habits are independent determinants of the health behavior according to the model. The concepts of attitude, perceived norm, and personal agency are central to the model and were the key constructs guiding this study. Due to the IBM model's inclusion of concepts that are most predictive of behaviors, the theory appears to offer a comprehensive approach based on existing knowledge concerning mammography access.

Gaps in the Science of Mammography Utilization

Despite many programs to improve access and the utilization of mammography by low-income uninsured women, disparities persist (Cui et al., 2007; Sabatino et al., 2008; Smith, Cokkinides, & Brawley 2008; Tangka et al., 2006). Low-income, uninsured women have been understudied due to difficulty making initial contact (Paskett et al., 2008; Peek & Han, 2004). While door-to-door recruitment and the use of

surveys have been successful for recruiting other similar groups of participants, door-to-door recruitment in largely rural areas is time consuming and likely not cost-effective (Ahmed, Lemkau, Nealeigh, & Mann, 2001; Galen, Kaplan, & Pasick et al., 2007; Lauver, Martin, Uhler, & Workman, 2003). Typically, women are recruited from health care agencies for mammography studies; however, the recruitment of women from the community (i.e. non-health care agencies) is much less common.

Several theories have guided research to explain mammography behavior and improve access to mammography (Bailey et al., 2005; Pasick & Burke, 2008). Yet, no single theory or combination of one or two theories have been able to fully explain mammography behavior or the underutilization of mammography (Champion & Skinner, 2003; Champion et al., 2005; Lauver et al., 1997; Steele & Porche, 2005b). Many theoretically based interventions have been developed to address barriers to mammography, with the most frequently addressed barrier being cost. Despite providing no-cost mammography, underutilization remains an important problem that results in breast cancer disparities for subgroups of American women (Tangka et al., 2006).

Although the TPB/TRA and combinations of theories have been used as theoretical frameworks in mammography behavior research (Champion, 1991; Champion et al., 2005; Pasick & Burke, 2008; Steele & Porche, 2005a; Tolma, Reininger, Evans, & Ureda, 2006), no published studies were found using the most recent form of the IBM model. Use of the IBM model provides an opportunity to study many concepts that have successfully predicted intention in health behaviors (Montano

& Kasprzyk, 2008). In addition, the IBM model methodology suggests the use of elicitation interviews to identify population specific perceptions concerning mammography. An in-depth examination of the perceptions of uninsured, low-income women about mammography can provide new insights to address current disparities in mammography use and explain the underutilization of no-cost mammography.

CHAPTER 3

METHODS

Research Design

The purpose of this qualitative study was to explore factors influencing mammography utilization among uninsured, low-income Northwest Missouri (NWMO) women who qualify for no-cost mammography services. A narrative descriptive design was utilized to:

1. explore attitudes concerning mammography;
2. explore barriers and facilitators to mammography;
3. gain an understanding of factors influencing mammography behavior; and
4. identify information that may help to inform strategies to increase mammography access among uninsured, low-income women age 40 to 64 years in NWMO who have never had a mammogram.

Narrative description is a method that allows the discovery of the participant's perceived "facts" and views concerning a health behavior, such as mammography, while minimizing inference during the interpretation and analysis (Sandelowski, 2000).

Individual semi-structured elicitation interviews were conducted with uninsured, low-income NWMO women, were 40 to 64 years of age, and self-reported never having a mammogram. The Integrated Behavioral Model (IBM model) served as the framework for data collection to explore the attitudes, norms, barriers, and facilitators influencing

mammography behavior among underinsured, low-income women within NWMO (Montano & Kasprzyk, 2008).

The IBM Model has been previously explained in Chapter 2. Knowledge, skills, environmental constraints, and habits are independent determinants of the health behavior according to the model (see Figure 1 on p. 9). The concepts of attitude, perceived norm, and personal agency are central to the model and were the key constructs guiding this study (see Appendix B). While the IBM model was used to guide the interview questions for the study, the women were encouraged to fully express their experiences, beliefs, and feelings concerning mammography. Screening behaviors, including those for HIV, colon cancer, and breast cancer, have been investigated using the Theory of Planned Behavior, Theory of Reasoned Action and IBM model which use the same elicitation interview process (Montano & Kasprzyk, 2008). However, the qualitative data, used in instrument development, are rarely reported. This study used an interview guide to elicit responses for self-identified determinants that may influence mammography behavior. Other researchers have stressed the critical aspect of understanding the salience of a specific behavior, such as mammography, together with social norms, environmental constraints, and self-efficacy from the perspective of the focus population (Montano & Kasprzyk, 2008; Park, Buist, Tiro, & Taplin, 2008; Tolma, Reininger, Evans, & Ureda, 2006).

Use of the IBM model provided a comprehensive framework to understand the perspective of the target population concerning the health behavior of undergoing

mammography screening. Sandelowski (1993) suggests that theory is implicit in the problem identification, literature reviewed, and methodology used. Although an inductive approach is most often supported when conducting qualitative descriptive research (Sandelowski, 2000), the IBM model was selected to build on previous theoretical knowledge concerning women's behaviors when considering mammography. An established approach using elicitation interviews provided a unique focus on describing the participant's experiences with access to healthcare and specifically to mammography (Montano & Kasprzyk, 2008).

Protection of Human Subjects

The study procedures involving human subjects were reviewed and approved by the University of Missouri-Kansas City Social Sciences Institutional Review Board (SSIRB) (Appendix C), Missouri Western State University Institutional Review Board (Appendix D), and proposed recruitment sites. Adult women were recruited for the study at NWMO social service sites, such as food banks, job training centers, and a school supply distribution center. Each woman was approached by a research assistant (RA) or by the primary investigator (PI) and a screening guide was used to determine if inclusion criteria were met (Appendix D). The inclusion criteria included: Between the ages of 40-64 years, no insurance, and self-report of never having had a mammogram. Each potential participant was able to speak and understand English. No efforts were used to select women from a specific racial group. Each woman was informed that participation, or non-participation, in answering the screening questions and/or study would not impact

the current or future services they received at the recruitment site. Individuals who met the inclusion criteria self-disclosed their contact information if interested in participating. Interested individuals were contacted by phone by the PI and the purpose of the study and procedures for participation were explained. If the individual was interested in study participation, then an interview was scheduled at a private location chosen by the participant. Prior to beginning the interview, written informed consent was obtained from each participant (Appendix F). Participants were informed of their right to stop the interview process at any time and to skip questions if they were uncomfortable. Informed consents were kept separate from the interview and demographic information to protect confidentiality. Data were kept in a locked cabinet accessible only to the PI. All participants completed the interview process and received a \$25 gift card.

Settings and Sample

Recruitment efforts were conducted in various sites across NWMO to obtain a representative sample of women and unique mammography issues while also identifying common themes that cut across geography and situations (Patton, 2002). Access to the target population occurred through an established relationship that the PI had with the Community Action Partnership (CAP) of Greater St. Joseph, Missouri. Recruitment of participants took place at community and government agencies that provided services to low-income families in NWMO such as job training sites, food pantries and back-to-school fairs. CAP provides services in four counties within NWMO and also partners with other organizations, such as the Second Harvest Food Bank, to reach individuals

throughout all NWMO counties (CAP, 2010). These CAP sites were selected because qualifications for services provided by CAP were similar to the requirements for no-cost mammography. People who were receiving services from CAP sites had already been pre-qualified; therefore, individual income was not ascertained from participants to protect their privacy.

Strategies for recruitment were twofold: informational pamphlets placed at CAP service sites and area food banks and direct recruiting at those same sites. The PI met with the workers at the food banks to explain the study and discuss the opportunity to participate. In addition, the PI conducted face-to-face recruitment at service sites. One example was a “Back to School” Fair sponsored by CAP that provided school supplies, and health care information for low-income families. The PI had an informational table at the Back to School Fair that provided information about the importance of handwashing and also gave out healthy snacks and water bottles. Women who came to the handwashing table were given information about the study by the PI and research assistant (RA) while their children and grandchildren learned about hand washing. Women who expressed an interest in the study were screened to see if they met the inclusion criteria. Women who did meet the criteria and wanted to hear more about the study were given more information. If women expressed an interest to participate, they were verbal consent and their contact information so they could be called to schedule a study interview in the future. Direct face to face information about the study provided at

CAP events resulted in successful recruitment. No participants were recruited as a result of pamphlets that were simply placed in agencies.

Inclusion criteria for the study were: (1) uninsured NWMO resident, (2) female 40 to 64 years of age, (3) ability to speak and understand English, and (4) family income below 250% of federal poverty level (FPL). Screening mammography is suggested to begin at the age of 40 years for women of average risk. Women 65 years of age and older are eligible for Medicare and may have different barriers; therefore, women 40-64 years, within the range of women recommended to receive a mammogram, were the population of focus. Income criteria were selected based on qualifications for programs offering no-cost mammography. Income below 250% of FPL qualifies women for no-cost mammography screenings funded by the National Breast and Cervical Cancer Early Detection Program (Missouri Department of Health and Senior Services, 2008). Based on estimates using the 2006 U.S. Census and the DHSS County Level Study 2007, a pool of approximately 19,000 uninsured women and 17,000 women (36%) who had not had a mammogram in NWMO existed (Missouri Department of Health and Senior Services, 2007b; U.S. Census Bureau, 2006).

Measures

Recruitment Screening Tool: A screening tool was developed for this study (Appendix E). The screening tool was used to identify women who met the inclusion criteria and obtain contact information to schedule the interview.

Interview Guide: An interview guide was used to elicit data about barriers and facilitators for mammography screening. The theory-based questions are derived from the IBM model (Appendix B).

Demographic Data Collection Form: This form was used to collect information about the participant's age, race, income, education, and mammography screening behaviors after the interview (Appendix G).

Procedures for Data Collection

After IRB approvals, recruitment of participants commenced. Sixty-four women were screened, 12 met study criteria. All women who met study criteria participated in the study. One woman, who did not qualify for the study, took a copy of the flier to a friend who called the PI and asked to participate in the study. Ten women (83%) were interviewed in their own homes. The remaining two women (17%) were interviewed in the private university office of the PI. Before initiating each interview, informed consent (Appendix F) was obtained and the participant was provided with a copy of the consent form for their records. Semi-structured individual interviews (Appendix B) were audio-taped (Patton, 2002). Each woman was informed of her right to stop the interview at any time. There was no time limitation for the interviews; the average length was one hour (range=35-80) minutes. At the end of each interview, demographic data were collected: age range, race/ethnicity, education level, marital status, and family history of breast cancer. Women were also asked if they had considered having a mammogram and whether they had ever had anyone suggest that they have a mammogram. After

completing the interview, each participant was given a \$25 department store gift card for their time, a packet that included women's health care information, and a calendar of no-cost health-related activities in their community.

The interview guide provided a structure for the data collection. Follow-up and probing questions were also used to clarify and expand upon the participant responses (Patton, 2002). For example, when asked about where the participant obtained healthcare information, follow-up questions were asked exploring their opinions about specific methods used or information provided (Susan G. Komen for the Cure Greater Kansas City Affiliate, 2009). After two of the interviews were complete, follow-up questions were focused more on cost and knowledge about no-cost mammography programs to provide further clarification. Questions were asked such as "You've identified cost as a major reason for not obtaining a mammogram. How much do you think that a mammogram costs? Are you aware of any programs that provide free mammograms?"

Data Analysis

Demographic data were analyzed using descriptive statistical methods. Each audio-taped interview was transcribed verbatim and proofed by comparison to the audio-tape (Sandelowski, 1995). During transcription, the transcriber listened to the spoken word and documented feelings expressed. In addition, field notes were reviewed and facial expressions and other non-verbal communication documented during the interview were added to the transcriptions and considered in the data analysis. Initial data analysis

began after two interviews were completed to review participant responses and to refine questions to elicit additional information concerning mammography access. Data collection and concurrent data analysis continued until saturation was reached. Transcripts were read multiple times to provide immersion and familiarity with the content and then analyzed for recurring themes using content analysis (Lincoln & Guba, 1985; Sandelowski, 2000). The PI who conducted the interviews and the PI's faculty mentor, who was not involved in data collection, coded all data independently, with codes developed by consensus. Related coded data were grouped together to detect themes that exemplified an experience reported by participants in response to each interview question. Although a deductive approach was used for data collection using the IBM model, an inductive approach to analysis was conducted to discover patterns and themes from the interview data. An audit trail document decisions and comments regarding analysis procedures in a narrative journal (Patton, 2002).

Once coded, these statements were merged, combined, and collapsed into themes. Each theme exemplified an experience reported by the participants in response to each interview question. Thus, the outcome of this study was a universal description of the healthcare access related to mammography among the study population. Coded data were grouped and assigned tentative category labels. Related content were grouped together in order to detect themes. In order to verify validity of the analysis, an audit trail documented decisions and comments regarding analysis procedures in a narrative journal.

CHAPTER 4

RESULTS

The purpose of this qualitative study was to explore factors influencing mammography utilization by a group of uninsured, low-income women (n=12) ages 40 to 64 years residing in northwestern Missouri (NWMO). Participants for the study were recruited from community agencies that offered social services to low-income families in NWMO. Semi-structured individual interviews were conducted with the use of an interview guide based in the Integrated Behavioral Model (IBM model).

Data were obtained from 12 women. Most women (n=10) lived in rural settings defined by Stanhope and Lancaster (2010) as requiring at least 30 minutes or longer to commute to a metropolitan area. Demographic data were collected after completion of the interview to describe the study participants (See Table 6).

Themes

There were four themes that emerged from these data: *Competing Priorities, the Costs of Having a 'Free' Mammogram, Attitudes about mammography* and *Navigating the 'Red Tape'*.

Theme 1: Competing Priorities

The women in this study had many competing needs and very limited resources. Each woman discussed how she made daily choices about how to best provide for herself and her family. Accessing health care screening services (i.e. mammography) was viewed as a very low priority, compared to other needs such as meeting the family

needs for food, shelter and childcare (for children and grandchildren). In general, these women placed their own health needs last.

Table 6

Demographics

Age	N	Percent
40-49	6	50%
50-59	3	25%
60-64	3	25%
Marital Status		
Not married	1	8%
Married	5	42%
Separated	1	1%
Divorced	4	33%
Widowed	1	8%
Education		
High school or equivalent	3	25%
Some college/trade school	6	50%
College degree	3	25%

(Table continues)

Table 6

Demographics(continued)

First degree relative with breast cancer		
Yes	7	58%
No	5	42%

All women worked hourly jobs and described a need to work as many hours as possible to “stretch” their financial resources to meet the priority needs of food and shelter. For one woman who did make getting a mammogram a priority, “it didn’t work out”. This woman described her inability to obtain a mammogram. She discovered a breast lump, took time away from her three part-time jobs and arranged transportation by her daughter (who also had to take off work). When she arrived at the mammogram center, her appointment had been cancelled. The center had tried to call her but missed her because she left home one hour before the appointment due to living in a rural location.

The need to take care of their family was a recurring competing priority. Almost half of the women interviewed (n=5) had their adult children living with them due to a lack of financial resources and/or catastrophic events. It was important to the women that her family’s needs be met first, before her own needs were addressed. Often the family’s resources had to be pooled to meet needs. Women were consumed with family

responsibilities and had no time for their own health. As illustrated by one woman: “They [two adult sons] take up my time and energy...and money.” Another woman explained that since she couldn’t afford insurance for the whole family, she would not obtain personal health insurance. She stated, “You can’t just choose one person to cover or at least I can’t, I’m not going to do it.” She explained that she had seven children; five grown children lived with her. She could afford insurance for herself, but she placed the needs of her entire family before that of healthcare or obtaining personal insurance.

Attending to chronic health problems such as asthma, diabetes, arthritis, hypertension, and heart disease took priority over preventive/screening health needs. Even chronic health problems only became a priority when “out of control” As one woman stated:

“I don’t go to the doctor unless I absolutely have to...unless I’m practically dead...then I go to the emergency room.” Another explained: “If I started having some sort of problem that I couldn’t figure out on my own-or that scared me-that is about the only thing that would get me to go back (seek healthcare)...there’s other things to be done in this world that are far more important.”

She identified that her family, their needs, and even the needs of her farm were more important than healthcare.

Theme 2: The Cost of a ‘Free’ Mammogram

The cost related to obtaining a mammogram outweighed the potential benefits for many of the women. Although the mammogram itself might be “free” there were many

other costs associated with obtaining a mammogram. Many discussed penalties that they would incur in the workplace for taking time off work, in addition to lost wages. The long distance to the mammogram center was a problem for these NWMO women, as public transportation did not exist. If they did have personal transportation, it was unreliable and too expensive to drive. When women did have insurance (insurance status changed frequently), the money for the co-pay for a doctor's visit to obtain a referral for a mammogram was cost prohibitive. In addition, some of the women would need to pay for daycare (for children and/or grandchildren) in order to take the time to have a mammogram. Women also discussed hidden costs such as the long distance phone charges or lack of cell phone minutes to make an appointment for a mammogram. One woman summed up the issue of cost in this manner: "If we could get a free mammogram that would be great, but if we have to go the big city to get it, take time off work and get daycare...that would be a big deal." Therefore, the "cost" of a mammogram was actually much more than just the actual cost of the mammogram itself.

Theme 3: Attitudes about mammography: Advantages and Disadvantages

The women interviewed in this study had conflicting attitudes about mammography. The women voiced what they viewed as advantages and disadvantages to having a mammogram. The women all agreed that "knowing one way or the other" about a breast cancer diagnosis would be the primary advantage of getting a mammogram. Many could articulate that early detection and early treatment of breast cancer was a benefit of mammography. As one woman explained: "A few years ago, you

know... it was probably a comfort issue...I thought it would be uncomfortable. But now, I think it [receiving a mammogram] would give me piece of mind.”

Women were somewhat fearful about mammography and described their perceptions about the mammogram procedure. Many felt that a mammogram would cause discomfort or pain. These negative perceptions were often based on the mammogram experiences of a family member or friend. The following statements illustrate the perceptions women had about having a mammogram:

“I talked to some people and they say it’s uncomfortable...People scare you by saying it’s painful and women and pain don’t get along (laughter) ...they push your breasts against something flat and it’s painful.”

Despite recounting fears and negative experiences from family and friends, women stated that ‘everyone’ would be supportive of them receiving a mammogram.

Women also described a sense of uncertainty concerning the potential outcomes of the mammogram. Women were worried about having a positive result and about how they would feel. A few discussed the pros and cons of getting a positive mammography result. Women described a fear of a breast cancer diagnosis weighed against the worry of not knowing one way or the other. “In not knowing, I don’t have to worry about anything but I could know... In some ways it is better to just stick my head in the sand and not know.” A few stated that a cancer diagnosis was nothing to worry about. For example, one stated, “They could find out that it was in the early stages and they could treat it”.

Theme 4: Navigating the ‘Red Tape’

These women described experiences in which she had a health care need, attempted to access “free” or low-cost health care services, and had difficulty with qualifying for services or being left with a bill that she found challenging to pay. Two women had attempted to access no-cost mammography services. One woman reported making numerous phone calls several times and finally had to give up trying to obtain financial assistance for her mammogram. She finally had just scheduled a mammogram and she was planning to pay for it out of pocket. The women told stories about the challenges that they, a friend, or a family member had in accessing low or no-cost health care services. Problems navigating the ‘red tape’ in order to qualify for financial assistance were common. Women described a need for more information about how to “navigate the red tape”. The following quotes illustrate the problems women encountered when trying to access free mammogram programs:

“I think if there would be more information [available] about getting a free one [mammogram] and if you didn’t have three or four days of red tape so you could just go and say, ‘I don’t have any insurance and I need a mammogram’.” “If you go to the social services offices, they don’t give you any information on anything that could help you. They just tell you that you can’t have this [Medicaid]. They tell you your income is too high and they mail you a nice little letter that you make too much money. They don’t educate you on anything that might be available.”

Due to a lack of knowledge concerning available resources and locations of services women often mention obtaining “back door” access by calling friends who work with healthcare providers for advice and assistance. Some of the women interviewed were not even aware that free or low-cost mammography programs existed. Of those who were aware of no-cost mammography, most did not realize that they met the financial criteria and were eligible for the National Breast and Cervical Cancer Early Detection Program. However, women did express a willingness to have a no-cost mammogram:

“I would do it [have a mammogram]. I mean it, why wouldn't I? I don't understand why I wouldn't if it were free....I don't know if you can get it for free anywhere. If I could, I would get it because I think it is really important. Early detection of anything is important.”

Women discussed their frustrations with trying to qualify for free or low-cost services. Qualification processes and providing documentation (birth certificates, marriage licenses/divorce papers, Social Security numbers) were difficult due to the many phone calls and additional trips to government offices required. Some attempted to obtain necessary documents and obtain information, but often left empty handed. Their experiences were described as “falling through the cracks” or being “in between” those who have enough money for insurance and those who qualify for Medicaid. As one woman explained:

“It gets kind of discouraging...you do your best but you fall through their cracks because your income is too high for this yet you don’t have money to pay for everything and I don’t understand our system sometimes.”

Many women discussed having general information concerning mammography, and they knew they needed a mammogram, but they did not verbalize having the skills to access the free mammogram. One woman even showed that she had a mammography brochure but it did not have the information that she needed stating:

“I guess that if I had it [the information] right in front of me, this is the phone number, this is where you go and that would be a whole lot easier. As it is, I don’t know where to go.” Another supported the same theme: “I guess the information that I have read has been general, that you should get it done. The specific where to go and telephone number isn’t included. I understand that it needs to be done, but it needs to be a specific place and time.”

Finally, women simply lacked motivation as illustrated by one as:

“Mostly it is a matter of making the time and set it up and take the initiative to get it done. No one is going to do it for me...it is just hard to get started in it.”

Discussion

The purpose of this narrative descriptive study was to identify barriers to no-cost mammography services among a group of low-income women living in Northwest Missouri. Individual interviews were conducted, with the interviews guided by the IBM model. Findings indicated that the women in this study had competing needs and limited

resources that impaired their ability to access no-cost mammography services.

Consistent with the IBM model, women shared positive attitudes and perceived norms that would normally be associated with the behavioral intention (motivation) to obtain a mammogram. Positive attitudes concerning the benefits of mammography included early detection and treatment of cancer; however these were not enough to motivate women to engage in a mammography screening. Although perception of benefits are often cited as a motivator to mammography attendance (Champion & Skinner, 2003), barriers are identified as more influential than benefits on behavior, especially when there is more than one barrier (O'Neill et al., 2008). The hidden costs of having a mammogram were the barrier most often discussed by the women interviewed in this study. These “hidden” costs are often not considered when no-cost mammography programs are developed.

O'Neill et al. (2008) suggests behavioral intentions do not always lead to the reality of obtaining a mammogram; the lack of action toward mammography attendance may be due to a lack of implementation intentions, or a breakdown of the behavior into smaller, step-by-step actions. For example, in order to obtain a mammogram, in addition to the desire to obtain a mammogram, women may need to find out a location that provides mammography, pre-qualify for no-cost services, schedule the mammogram, schedule time off work, secure transportation, and put actions in place that will take care of any family commitments (e.g. childcare). The IBM model supports the inclusion of knowledge and skills to get a mammogram, salience of the behavior, environmental constraints, and habit. These additional constructs of the IBM model may assist in

explaining the lack of action and point to possible interventions to increase mammography attendance.

Lacking a healthcare provider referral has often been reported in the literature as a determinant for mammography (Champion & Menon, 1997), yet for low-income women with a healthcare provider, up to 25% may not receive a referral (Bazargan, Bazargan, Calderon, Husaini, & Baker, 2003). The population of focus in this study was women who did not have a relationship with a healthcare provider. Only two of the women interviewed stated that they had ever been referred for a mammogram. The lack of referrals for this group of women may be correlated to the fact these women primarily saw healthcare providers only in emergent situations (i.e. Emergency Departments). Women experienced competing priorities and obtaining a mammogram came last after attending to family and other basic personal needs. This finding is consistent with other studies that have investigated the culture among low-income, rural populations, where low priority was a theme associated with regard to practicing preventive health (Murimi & Harpel, 2010). In the Murimi and Harpel study, participants also described similar competing priorities where family needs came first, well before personal preventive health care.

Navigating the “red tape” was a theme that emerged from the findings. According to the IBM model, navigating the “red tape” may fall under the constructs of knowledge and skills, as well as environmental constraints which independently influence behavior (See Figure 1, p. 7). Women expressed a need for navigation

assistance with explaining available resources, prequalifying for services, initiating a relationship with a healthcare provider, and assisting with unique barriers to access services.

In this study, women referred to “red tape” associated with qualifying for services and lack of awareness concerning available resources and basic information (location and times) concerning services. Knowledge and skills could be enhanced by the use of a community patient navigator. A patient navigator could also be helpful in knowing the processes to qualify for services including sources for documents required to apply as well as locations and times for available mammography services within the community. Lay health advisors have been effective in increasing positive attitudes (Flax & Earp, 1999). Although case management may also be useful, this intervention is usually enacted after an individual has accessed a health care agency or received results from a mammogram indicating cancer may be present. Case management or patient navigators have been used successfully to guide women who have a positive mammogram through diagnosis (Ell, Vourlekis, Lee, & Xie, 2007; Lobb, Allen, Emmons, & Ayanian, 2010) and have been used to implement programs to increase mammography use with diverse populations (Ell et al., 2007; Hiatt et al., 2001; Sherrod & Richardson, 2003).

Women also need assistance with balancing competing priorities and environmental constraints. Environmental constraints identified in this study include lack of knowledge concerning no-cost mammography programs among some rural

providers and other systems barriers such as communications (printed education, methods of publicizing services, lack of phone access). One woman provided a copy of a government published educational flier that provided statistics on breast cancer and told the general importance of mammography. This woman and others who participated identified the need to have specific information including local contact information with a schedule, and list of documents needed to qualify for services. Tailored print messages have been effective in increasing mammography utilization (Champion et al., 2007). In addition, the women provided specific suggestions on where to post educational information in their communities. For example, two women suggested posting information on the community notice board at the local gas station/convenience store. Participants stated that most people in their community regularly read the information on these boards.

A strength of this study was the use of the IBM model. The IBM model focused on a number of constructs from theories that have individually, or in combination with others, been successfully used in the study of mammography utilization (Pasick & Burke, 2008). Based on the results of this study, interventions to enhance mammography uptake should be considered to enhance attitudes (priorities), knowledge (concerning available resources), and skills (to qualify and access services) as well as methods to overcome environmental constraints (scheduling and transportation). Programs such as lay advisor/patient navigator, which have been successful in other populations, may be able to assist NWMO women with engagement in mammography screening.

Findings from this study will be used to develop targeted interventions to increase mammography utilization for NWMO women. In order to effectively target important factors that may influence this population's mammography utilization, a quantitative assessment of important factors that influence mammography behavior in this population is necessary (Montano & Kasprzyk, 2008). Therefore, the next step in this program of research is to use the IBM model as a framework to guide the development of a questionnaire to be used to empirically ground the focus of the interventions and provide a method of outcome measurement.

CHAPTER 5

SUMMARY, CONCLUSIONS, LIMITATIONS, RECOMMENDATIONS, AND IMPLICATIONS FOR PRACTICE

Summary and Conclusions

The purpose of this study was to identify factors that prevent uninsured, low-income women from Northwest Missouri (NWMO) from accessing no-cost mammography services. A narrative descriptive design was used to: (a) examine attitudes concerning mammography, (b) gain insight into perceived barriers and facilitators to mammography, (c) gain an understanding of factors influencing mammography behavior, and (d) identify potential strategies to increase mammography access and utilization among uninsured, low-income women age 40 to 64 years in NWMO who have never had a mammogram.

The Integrated Behavioral Model (IBM model) served as the framework for data collection to explore the attitudes, norms, barriers, and facilitators influencing mammography behavior among underinsured, low-income women within NWMO. (Montano & Kasprzyk, 2008). The IBM model was used to develop an interview guide to address the overall purpose and specific aims of this study. Participants for the study were recruited from community agencies that offered social services to low-income families. Data were collected through individual semi-structured interviews (n=12).

Findings indicated that the women in this study experienced competing priorities and viewed screening behaviors, such as mammography, as a low priority. The cost

related to obtaining a mammogram outweighed the potential benefits for many of the women. Although the mammogram itself might be “free” there were many other costs associated with obtaining a mammogram including lost wages, transportation, co-pays related to provider visits for referral, travel, and telephone charges. The women had conflicting attitudes about the advantages and disadvantages of mammography and their perceptions about mammography were greatly influenced by family and friends. Women experienced barriers in the amount of “red tape” encountered when navigating the healthcare system in order to obtain a “free” mammogram.

In conclusion, this study provided nurses and other health professionals with a better understanding of determinants influencing low-income, uninsured women’s intention and desire to have a no-cost mammogram. Findings from this study may be used by public health providers to enhance mammography uptake through existing programs. In addition, findings may inform theoretically-based interventions to help reduce barriers and increase utilization of no-cost mammography programs by eligible women.

Limitations

This study had several limitations that warrant discussion. The primary limitation was that the women who volunteered as participants may be those who are most interested in their health. Hence, participants may not be representative of the entire population of NWMO women who qualify for no-cost mammography and do not use the services. Another limitation was that the study sample was limited to one geographic

location and all participants had received at least a high-school education. Women from other geographic locations or with less education may experience different barriers with regard to non-attendance at no-cost mammography programs. Finally, these findings may not be transferable to women who are not accessing mammography who are from other ethnic and cultural backgrounds. Despite these limitations, this study provides a better understanding of the socio-cultural context of mammography non-attendance among low-income, Midwestern women.

Recommendations for Future Research

As healthcare financing changes as a result of new legislation, nurses and other healthcare providers should continue to research barriers outside of cost that inhibit healthcare access. Research of populations who do not have a relationship with a healthcare provider is critical to address specific unmet needs of low-income populations. Use of social service agencies as a primary recruitment site in future studies may continue to provide access to this population. Although recruitment fliers provide a method of advertising a study, face-to-face recruitment methods provided a more effective means for enrolling participants.

Additional research can be conducted using the IBM model to guide intervention studies for women at different stages of mammography adoption in different geographic regions. Future studies using qualitative methods (elicitation interviews) as an initial step to determine a population's needs, priorities and attitudes may inform intervention

development. Use of the IBM model may provide a means to assess outcomes using instruments specifically reflecting the values and attitudes of the study population.

Implications for Practice

Mortality due to late-stage breast cancer remains disproportionately high for low-income, uninsured women (Byers et al., 2008; Peek & Han, 2004) and mammography is the best method for early detection of breast cancer. Despite many theoretically-based research studies and intervention programs that have been conducted to increase mammography use (Champion, Ray, Heilman, & Springston, 2000; Crane, Leakey, Ehrsam, Rimer, & Warnecke, 2000; Hall, Hall, Pfriemer, Wimberley, & Jones, 2007; Kreuter et al., 2006; Paskett et al., 2006; Taplin et al., 2000; Valdez, Banerjee, Ackerson, & Fernandez, 2002), a large segment of American women remain unscreened for breast cancer (Sabatino et al., 2008). Despite the fact that programs such as NBCCEDP and ENCOREplus exist, there are additional barriers that prevent women from utilizing no-cost mammograms.

Based on the results of this study, women may not have knowledge concerning these programs. Nurses should provide education that includes details about how to access a no-cost mammogram including: Places that provide services, times of operation, qualification criteria (where to obtain these documents), and where to find additional support services. Women in this study suggested providing education about support programs in local venues such as community centers and churches. Nursing interventions should be in the areas of attitudes (priorities), knowledge (concerning

available resources), and skills (to qualify and access services) as well as methods to overcome environmental constraints (scheduling and transportation).

Understanding individual and contextual issues for NWMO women may contribute to practice innovations to increase no-cost mammography utilization among individuals who do not routinely seek health promotion and early detection services. Early detection of breast cancer through mammography among low-income women has the potential to decrease mortality and breast cancer disparities in this population (Halliday, Taira, Davis, & Chan, 2007; Mobley et al., 2008).

Outcomes of this study

In conclusion, the following goals of this study have been met:

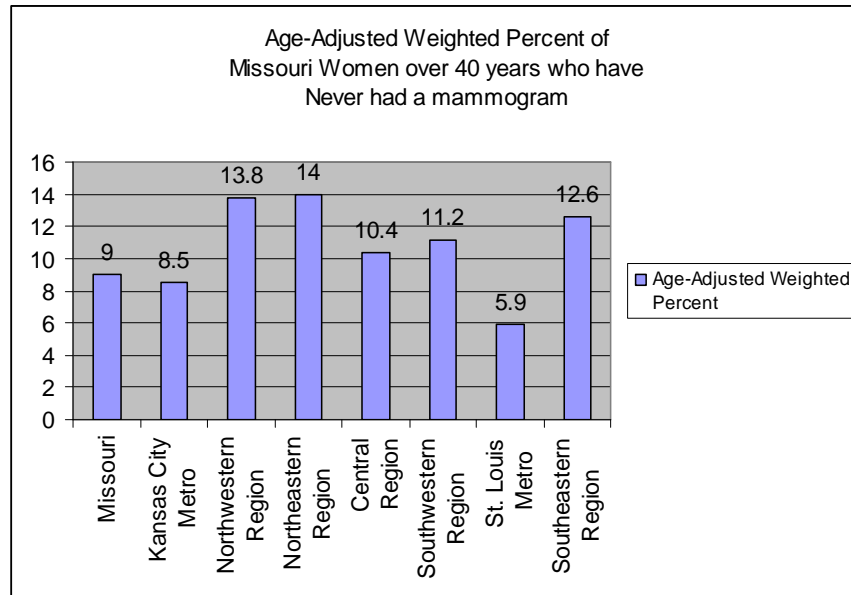
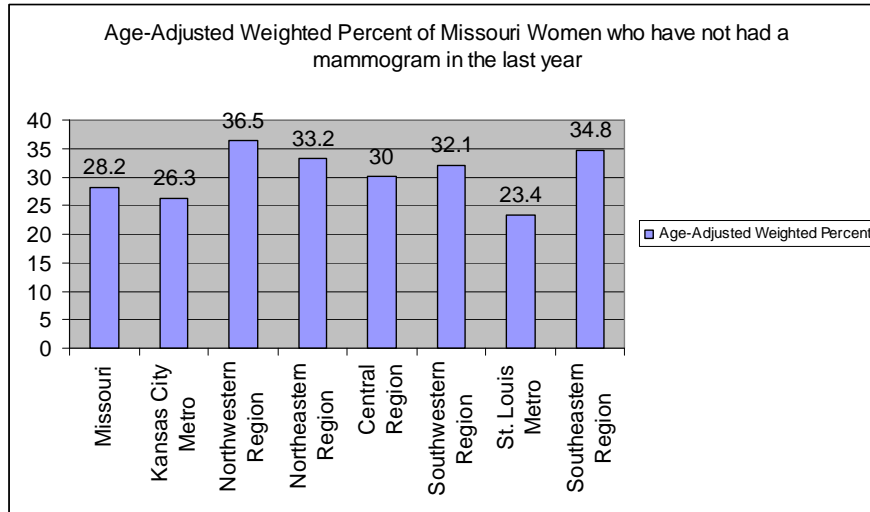
1. The goal to examine attitudes concerning mammography were identified which included advantages and disadvantages associated with having a mammogram.
2. Insight was gained into perceived barriers and facilitators to mammography. Women identified the true costs of having a “free” mammogram, and navigating the “red tape” of applying for healthcare services as barriers. Women identified that their family and friends would be supportive of them receiving a mammogram and that having knowledge concerning no-cost services would be a facilitator.
3. An understanding of the factors influencing their mammography behavior was gained, again, through the awareness that the women in this study were not all aware of the services that were available. Of those that were, two had experienced problems with access.

4. Potential strategies to increase mammography access and utilization among uninsured, low-income women age 40 to 64 years in NWMO who have never had a mammogram were identified through suggestions gained in interviews and through the results of data analysis. A community patient navigator or lay health advisor may provide a strategy for improving access and increase utilization of mammography services. Results of this study may be used in the next step of research developing a quantitative measure that will assist in targeting interventions to change behavior among women who are currently not accessing no-cost mammography.

APPENDIX A

NORTHWEST MISSOURI MAMMOGRAPHY STATISTICS

NORTHWEST MISSOURI STATISTICS



(Missouri Department of Health and Senior Services, 2007b).

APPENDIX B
INTERVIEW GUIDE

INTERVIEW GUIDE

	IBM Model Construct	Definition	Interview questions
A T T I T U D E	Experiential Attitude	Feelings that exist concerning obtaining a mammogram	What do you think will happen if you get a mammogram? How do you feel about that?
	Instrumental Attitude	The value placed on obtaining a mammogram.	What are the advantages or plusses of getting a mammogram? What are the disadvantages or minuses about getting a mammogram?
P E R N O R M I M I V S E D	Normative Influence	Beliefs concerning who or what may influence the behavior of obtaining a mammogram	Who would support you getting a mammogram? Who would not support you getting a mammogram? Where do you get information concerning health care? What places where you get information support you getting a mammogram? What places where you get information don't support you getting a mammogram?
P E A R G S E O N C A Y L	Perceived Control	Perceived ability to overcome barriers to obtain a mammogram	What things would make it easier for you to receive a mammogram? What things make it more difficult for you to receive a mammogram?
	Self-Efficacy	Perceived ability to obtain a mammogram	If you wanted to get a mammogram how certain are you that you can? What kind of things would help you overcome any barriers to get a mammogram?

APPENDIX C

UMKC SSIRB APPROVALS

UMKC SSIRB APPROVALS

From: Hughes, Germaine
Sent: Tue 1/22/2008 2:32 PM
To: Harris, Crystal R. (UMKC-Student)
Cc: Good, Megan; Siska, Kathylene
Subject: SSIRB Protocol # 071115 - Experiences Accessing Women's Health Services and Mammography among the Under-Insured

Crystal Harris, MSN, RN
6085 NW Martin Road
Kansas City, MO 64164

Approval Date: January 22, 2008

RE: Protocol # 071115 - Experiences Accessing Women's Health Services and Mammography among the Under-Insured

Dear Ms. Harris:

This is to inform you that your project proposal listed above was reviewed through the Social Sciences Institutional Review Board's expedited review process and has received approval under Category 7 of the categories of research that may receive expedited review. You may therefore proceed with your study. Notwithstanding the SSIRB's approval to conduct the study, in the following situations you must provide timely additional information in order to maintain the SSIRB's approval.

1. The SSIRB cannot approve studies for more than one year. Unless the SSIRB renews its approval, your authority to conduct this study will expire on the anniversary of this letter. To request a continuation of your authority to conduct the study you will need to submit a completed Research Progress Report to the SSIRB office. Your authority to conduct the study cannot be continued until your completed Research Progress Report has received the necessary SSIRB review and approval. Therefore, you need to submit the completed Research Progress Report at least one month prior to the anniversary date of your project's approval/reapproval. The date of this letter is the approval date for your study. However, if your study requires more than one extension, the applicable anniversary date may change from year-to-year. Consult your most recent approval/reapproval

letter for the applicable anniversary date. Call the SSIRB office if you have questions about this.

2. If you want to make a change to the study, you must obtain the SSIRB's prior approval of the change.
3. If you want to add or delete investigators from the study, you must obtain the SSIRB's prior approval of the addition or deletion.
4. If a participant in your study is injured in connection with their participation, you must inform the SSIRB regarding this adverse event in a timely way.

Please inform the SSIRB when you complete the study.

If we can be of further assistance, please don't hesitate to call the SSIRB office at 816-235-1764. Best wishes for a successful study.

PLEASE NOTE:

If you are using a signed consent form you must use the copy of the consent form that has been stamped and approved by the SSIRB, which is attached, before you begin consenting subjects. All subjects must be consented on a copy of the approved consent form with the SSIRB Stamp.

If requested, a hard copy of the stamped consent can be mailed to you.

Thanks,

Ms. Germaine Hughes

Administrator

Social Sciences Institutional Review Board

University of Missouri - Kansas City

5319 Rockhill Road

Kansas City, MO 64110-2499

Office: 816-235-1764

Fax: 816-235-5602

hughesge@umkc.edu

This e-mail is an official notification intended only for the use of the recipient(s). This letter indicates the status of the UMKC Social Sciences IRB review of the referenced research project. When appropriate, a member of the UMKC Social Sciences IRB staff will be contacting the recipient(s) informing them of other IRB documents related to this project that are available to either 1) be picked up at the IRB office - 5319 Rockhill Road or 2) be mailed via campus mail or postal service - i.e.; revisions to consent form, advertisements, etc. If a signed copy of this letter is needed, please contact a member of the IRB staff. If you have received this communication in error, please return it to the sender immediately and delete any copy of it from your computer system.

Approval Date: December 3, 2008

Crystal Harris, MSN, RN
6085 NW Martin Road
Kansas City, MO 64164

RE: Protocol # 071115 - Barriers to no-cost mammography screening among uninsured women

Dear Investigator:

Thank you for submitting a progress report on your research protocol. Your study was reviewed through the board's expedited review process and has been reapproved under Category 7 of the categories of research that may receive expedited review.

You have also requested an amendment to the research proposal listed above. The amendment request seeks to:

1. Revise the title of the study to "Barriers to no-cost mammography screening among uninsured women."
2. Remove Dr. Peggy Ward-Smith from the study team.
3. Remove the Social Welfare Board as a study site.
4. Add the YWCA and agencies of the Community Action Partnership of St. Joseph as study sites.
5. Initiate a screening tool for recruitment.
6. Revise study consent form to reflect the changes described in this amendment.
7. No longer conduct interviews at Social Welfare Board.
8. Revise the interview guide based on the Integrated Behavioral Model.

This amendment is consistent with the purposes of the study and will permit the collection of relevant data. Consequently, following an expedited review process the Social Sciences Institutional Review Board has approved your amendment request .

You have full approval of the attached consent form date stamped 12/3/2008 thru 12/2/2009.

Notwithstanding the SSIRB's reapproval to conduct the study, in the following situations you must provide timely additional information in order to maintain the SSIRB's approval.

1. The SSIRB cannot approve studies for more than one year. Unless the SSIRB renews its approval, your authority to conduct this study will expire on the anniversary of this letter. To request a continuation of your authority to conduct the study you will need to submit a completed Progress Report Form to the SSIRB office. Your authority to conduct the study cannot be continued until your completed Progress Report form has received the necessary SSIRB review and approval. Therefore, you need to submit the completed Progress Report Form at least one month prior to the anniversary date of your project's approval/reapproval. (The date of this letter is the approval date for your study. However, if your study requires more than one extension, the applicable anniversary date may change from year-to-year. Consult your most recent approval/reapproval letter for the applicable anniversary date. Call the SSIRB administrator if you have questions about this.)
2. If you want to make a change to the study, you must obtain the SSIRB's prior approval of the change.
3. If you want to add or delete investigators from your study, you must obtain the SSIRB's prior approval of the addition or deletion.
4. If a participant in your study is injured in connection with their participation, you must inform the SSIRB regarding this adverse event in a timely way.

Please inform the SSIRB when you complete the study.

If we can be of further assistance, don't hesitate to call us at 816-235-1764. Best wishes for a successful study.

PLEASE NOTE:

If you are using a signed consent form you must use the copy of the consent form that has been stamped and approved by the SSIRB, which is attached, before you begin consenting subjects. All subjects must be consented on a copy of the approved consent form with the SSIRB Stamp.

If requested, a hard copy of the stamped consent can be mailed to you.

Thanks,

Ms. Germaine Hughes

Administrator
Social Sciences Institutional Review Board
University of Missouri - Kansas City
5319 Rockhill Road
Kansas City, MO 64110-2499
Office: 816-235-1764
Fax: 816-235-5602

RE: Study 071115: Barriers to no-cost mammography screening among uninsured women

From: hughesge@umkc.edu [mailto:hughesge@umkc.edu]

Sent: Thursday, November 12, 2009 3:51 PM

To: Harris, Crystal R. (UMKC-Student)

Cc: Hughes, Germaine; Anderman, Sheila H.; Chertoff, Keyna K.; Enriquez, Maithe; Neff, Kathleen A.

Subject: Study 071115: Barriers to no-cost mammography screening among uninsured women

November 12, 2009

Approval Date: November 12, 2009

Crystal Harris, MSN, RN
6085 NW Martin Road
Kansas City, MO 64164

RE: SSIRB Protocol #: 071115 - Barriers to no-cost mammography screening among uninsured women

Dear Investigator:

Thank you for submitting a progress report on your research protocol. Your study was reviewed through the board's expedited review process and has been reapproved under Category 7 of the categories of research that may receive expedited review.

You are granted permission to continue your study as described effective immediately. The study is next subject to continuing review on or before 11/11/2010.

You have full approval of the consent form version date 12/3/2008 SSIRB date stamped 11/12/2009 thru 11/11/2010 (which will follow in a separate email).

You have also requested an amendment to the research proposal listed above. The amendment request seeks to:

1. Remove Deborah Booram from the study team.

This amendment is consistent with the purposes of the study and will permit the collection of relevant data. Consequently, following an expedited review process the Social Sciences Institutional Review Board has approved your amendment request .

Notwithstanding the SSIRB's reapproval to conduct the study, in the following situations you must provide timely additional information in order to maintain the SSIRB's approval.

1. The SSIRB cannot approve studies for more than one year. Unless the SSIRB renews its approval, your authority to conduct this study will expire on 11/11/2010. To request a continuation of your authority to conduct the study you will need to submit a completed Progress Report Form to the SSIRB office. Your authority to conduct the study cannot be continued until your completed Progress Report form has received the necessary SSIRB review and approval. Therefore, you need to submit the completed Progress Report Form at least one month prior to the anniversary date of your project's approval/reapproval. (The date of this letter is the approval date for your study. However, if your study requires more than one extension, the applicable anniversary date may change from year-to-year. Consult your most recent approval/reapproval letter for the applicable anniversary date. Call the SSIRB administrator if you have questions about this.)

2. If you want to make a change to the study, you must obtain the SSIRB's prior approval of the change.

3. If you want to add or delete investigators from your study, you must obtain the SSIRB's prior approval of the addition or deletion.

4. If a participant in your study is injured in connection with their participation, you must inform the SSIRB regarding this adverse event in a timely way.

Please inform the SSIRB when you complete the study.

If we can be of further assistance, don't hesitate to call us at 816-235-1764. Best wishes for a successful study.

PLEASE NOTE:

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If requested, a hard copy of the stamped consent can be mailed to you.

Thanks,

Ms. Germaine Hughes
Administrator
Social Sciences Institutional Review Board
University of Missouri - Kansas City
5319 Rockhill Road
Kansas City, MO 64110-2499
Office: 816-235-1764
Fax: 816-235-5602
hughesge@umkc.edu

APPENDIX D

MWSU IRB APPROVAL

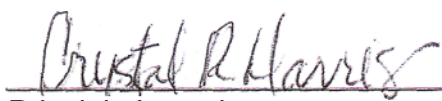
MWSU IRB APPROVAL

From: Missouri Western IRB Chair (Cronk, Brian)
<cronk@missouriwestern.edu>
To: <CRHARRIS@MISSOURIWESTERN,EDU>
Date: Friday - May 8, 2009 2:26 PM
Subject: [MWSC IRB] Status Update For Proposal 942
May 8, 2009

Dear CRYSTAL HARRIS,

Your proposal to the CUHSR entitled A STUDY TO IDENTIFY BARRIERS TO NO-COST MAMMOGRAPHY SCREENING AMONG UNINSURED, LOW-INCOME WOMEN IN NORTHWEST MISSOURI has been granted expedited approval. You are now authorized to begin data collection. When you are finished with the project, return to the CUHSR web site and submit a final status report. If your data collection takes longer than the 180 days that were approved, you will be required to file an extension, Your proposal has been assigned proposal id 942, Please record this number.

PLEASE PRINT THIS EMAIL, SIGN IT, HAVE YOUR DEPARTMENT CHAIR SIGN IT, AND FORWARD IT TO THE CHAIR OF THE CUHSR


Principle Investigator


Department Chair or Designee



Chair of the MWSC

CUHSR[https://groupwise.missouriwestern.edu/gw/webacc?User.context=gyluu2Naan
j5hefMic&Item.d,..](https://groupwise.missouriwestern.edu/gw/webacc?User.context=gyluu2Naanj5hefMic&Item.d,..) 5/11/20C

APPENDIX E

RECRUITMENT SCREENING TOOL

Recruitment Screening Tool

(To be administered verbally by the screener-Directions in italics)

Ask the questions in bold: The following information will be used only to describe the group completing the survey. All responses will be kept confidential.

What is your age?

less than 40

40-49

50-59

60-64

65 and over

Do you have insurance?

Yes

No

Have you ever had a mammogram?

Yes

When? _____

No

Would you be interested in being interviewed by a nurse about mammograms? You could choose a convenient place and time and it would take about one hour. Ask them to provide their contact information ONLY if they are interested in participating in an interview.

Name _____

Phone Number _____

Best time to contact you _____

APPENDIX F
CONSENT FORM

Consent Form

Version Date: Dec. 3, 2008
Page 1 of 2

Consent for Participation in a Research Study

Barriers to No-Cost Mammography Screening Among Underinsured Women
Principle Investigator: Crystal Harris MSN, RN
Faculty Supervisor: Maithe Enriquez PhD, RN, ANP

You are being invited to participate in a research study entitled *Barriers to No-Cost Mammography Screening Among Underinsured Women*. The aim of this study is to explore attitudes, barriers and facilitators about mammography, determine who or what may influence mammography use and identify what may increase mammography use in the community. Women's attitudes about mammography will be identified and described. Women over the age of 40 who are eligible for no-cost mammography will be eligible to participate. You must speak and understand English in order to participate.

As a participant in this study you will participate in a single audio-taped, individual interview that will take approximately one hour. The interview will be conducted in a private location of your choice. Participation in this study is voluntary and you may withdraw your participation at any time. Deciding not to participate or choosing to leave the study will not result in any penalty or loss of benefits to which you are entitled. If you decide to leave the study, the information that you have provided up to that point will not be used and any taped material will be given to you.




The anticipated benefits of your participation in this study are to identify things that make access to mammography easier or more difficult in your community. You will receive a \$25 gift card for participating in the study.

There are no physical risks associated with participation in the study. You may have negative feelings when talking about experiences. You have the right to stop the interview at any time if you feel uncomfortable.

All information that you provide during the study is treated confidentially. The interview will be conducted in a private location. Audiotapes of the interview will be transcribed by the primary investigator. All identifiable information will be removed from audiotapes and transcript. Audiotapes and transcripts of taped information will be stored in a locked cabinet. Demographic information and your consent will be kept separate from the tapes and transcripts. Transcripts will be used by the principle investigator and faculty advisors trained in confidentiality issues. All results will be reported as group data.

While every effort will be made to keep confidential all of the information you complete and share, it cannot be absolutely guaranteed. Individuals from the University of Missouri-Kansas City Institutional Review Board (a committee that reviews and approves research studies), Research Protections Program, and Federal regulatory agencies may look at records related to this study for quality improvement and regulatory functions.

Form Revision Date: 9/15/04

UMKC SOCIAL SCIENCES
INSTITUTIONAL REVIEW BOARD
INIT  APPRVD from:  to: 

The University of Missouri-Kansas City appreciates the participation of people who help it carry out its function of developing knowledge through research. If you have any questions about the study that you are participating in you are encouraged to call Crystal Harris, the investigator, at (816)271-4404.

Although it is not the University's policy to compensate or provide medical treatment for persons who participate in studies, if you think you have been injured as a result of participating in this study, please call the IRB Administrator of UMKC's Social Sciences Institutional Review Board at 816-235-1764.

For Questions please contact:
Crystal Harris, MSN, RN
4525 Downs Dr
St. Joseph, MO 64507
Phone: (816)271-4404
E-mail: crhr29@umkc.edu

Maithe Enriquez, PhD, RN, ANP
University of Missouri-Kansas City
2464 Charlotte
Kansas City, MO 64164
Phone: (816) 235-1711
E-mail: enriquezm@umkc.edu

Authorization

The nature of the study has been explained to me. I understand that my signature indicates my participation is voluntary. I understand that I can withdraw consent at any time. I have received a copy of the consent form.

Participant's Printed Name	Investigator's Printed Name
Participant Signature	Investigator's Signature
Date	Date

APPENDIX G

DEMOGRAPHICS COLLECTION FORM

DEMOGRAPHIC COLLECTION FORM

Demographic Data Collection Form (Completed by the participant at the interview)

The following information will assist us to describe the group that is participating in the study. Participation is voluntary so you may skip any questions that you do not wish to answer. All individual answers from this survey will be kept strictly confidential.

1. What is your age?

- | | |
|---------------------------------------|----------------------------------|
| <input type="checkbox"/> Less than 40 | <input type="checkbox"/> 60-64 |
| <input type="checkbox"/> 40-49 | <input type="checkbox"/> over 65 |
| <input type="checkbox"/> 50-59 | |

2. What is your racial or ethnic background? (Check all that apply)

- | | |
|--|--|
| <input type="checkbox"/> African American/Black | <input type="checkbox"/> Caucasian |
| <input type="checkbox"/> American Indian/Alaska Native | <input type="checkbox"/> Hispanic/Latino |
| <input type="checkbox"/> Asian/Pacific Islander | |

3. How would you describe your marital status?

- | | |
|--|------------------------------------|
| <input type="checkbox"/> Not married | <input type="checkbox"/> Separated |
| <input type="checkbox"/> Not married but living with a partner | <input type="checkbox"/> Divorced |
| <input type="checkbox"/> Married | <input type="checkbox"/> Widowed |

4. What is the highest level of education you have completed?

- | | |
|--|--|
| <input type="checkbox"/> Less than high school | <input type="checkbox"/> Some college/trade school |
| <input type="checkbox"/> High school or equivalent | <input type="checkbox"/> College Degree |

5. Do you have a usual place that you go when you are sick or you have questions about your health? No Yes If yes, where?

6. Are there places that you know about where you can get free health care or health care at lower rates? No Yes If yes, where?

7. Have any of your relatives had breast cancer?

Mother No Yes Don't know
Sister No Yes Don't know Not Applicable
Daughter No Yes Don't know Not Applicable

8. A mammogram is an x-ray of both breasts that looks for breast cancer. Have you ever considered having a mammogram? No Yes

9. Has anyone suggested that you go get a mammogram? No Yes

If yes, who made the suggestion (Please check all that apply)?

Physician

Nurse Practitioner

Friend

Relative

Other person: _____

This form is adapted from the Show-Me-Healthy Women demographic form

(Missouri Department of Health and Senior Services, 2010b)

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VITA

Crystal Harris was born in Kansas and raised in the Kansas City area. She attended local schools and graduated from Platte County R-3 High School. She then attended St. Luke's School of Nursing where she received a diploma in nursing, then becoming a registered nurse. Later she attended William Jewell College and received a Bachelor of Science in Nursing in Liberty, Missouri. She received her Master of Science in Nursing at the University of Kansas.

In 1986, Mrs. Harris began working at St. Luke's Hospital in Kansas City, Missouri as an oncology nurse. She worked there eight years providing patient care, eventually working as an assistant nurse manager and staff educator. She then began working at St. Luke's Northland Hospital where she started in staff education. She gained experience in quality management and was trained as a Baldrige Quality Evaluator. She held numerous management positions within the hospital setting. In 1994, she began work in home care and hospice where she stayed until 1999. Since that time she has been working as an assistant professor at Missouri Western State University. She is a current member of the Faculty Senate.

Mrs. Harris has presented at national nursing and academic conferences. She is the acting president of the Omicron Nu Chapter of Sigma Theta Tau International Nursing Honor Society, a member of the Council for Undergraduate Research, volunteer at the Komen Foundation, and instructor for the American Heart Association.