BREAST ABNORMALITIES: IDENTIFICATION OF INDICATORS THAT
FACILITATE USE OF HEALTH SERVICES FOR DIAGNOSIS AND TREATMENT
OF BREAST CANCER

by

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DEDICATION

I would like to dedicate this work to Maria: an uninsured mother, raising four children alone. She had an abnormal finding on mammogram, but had not returned for the recommended diagnostics. While a participant in an earlier study she said:

“When I am told I have a medical condition, I must live with the knowledge something is wrong. I am unable to afford to have it taken care of, so I would rather not know...

This is how working, poor people live”.

Her words serve as a reminder that health care should not be reserved for the privileged, but be accessible to all.

I would like to dedicate this work to the women who participated in this study. Their willingness to share of their time and experiences helps to develop understanding of health systems, the delivery of care and serves to shape interventions for the future.

I would also like to dedicate this work to my family for their continued support and encouragement. One must shed preconceptions, embrace new questions, and preserve a sense of wonder to be a life-long learner.
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ABSTRACT

**Problem:** There is a lack of knowledge about women who are screened for breast cancer, have an abnormal finding on mammogram, and then do not return in a timely manner for diagnostics and treatment. Lack of follow-up likely constitutes delayed treatment and poorer outcomes. Delays may result in later entry into the health system with advanced disease, more extensive and expensive care, burdening resources. Late stage breast cancer likely results in poorer health outcomes or early death.

**Purpose and Aims:** The purpose of this research is to describe contextual characteristics at the health delivery level as well as individual characteristics of women with abnormal mammography, and their association with use of follow-up health services. Particularly, this research examines the differences between women who are early and late responders after an abnormal mammogram.

**Population:** The participants were a convenience sample of 380 women who participated in mobile breast cancer screening. A subset of women with inconclusive or abnormal mammogram findings was the focus of analysis.

**Methods:** This research utilized a descriptive design with quantitative data collection through participant survey at mobile mammogram screening events in multiple urban and rural Arizona sites. Participants requiring further health care were followed by chart review. Analysis of correlations with the outcome variable: time to first follow-up appointment for recommended health care in women with abnormal mammograms was conducted.

**Findings:** Data indicated the time to the first follow-up appointment ranged from 1-110 days with follow-up for 77.4% of participants within 60 days, 6.5% within 60-90 days, and
16.1% without follow-up after 90 days. Significant relationships between contextual and individual characteristics and follow-up were found. Categories included organizational health system characteristics of geographic location, clinical breast exam and shared case management; individual characteristics of beliefs including value of health care; finance including out of pocket costs and perceptions of financial assistance; perceived needs including breast symptoms; and satisfaction with the last health visit and mammograms in general.

**Implications:** Recognition of barriers to follow-up after breast cancer screening is important for development of interventions to improve outcomes and has implications for screening and treatment management programs, community health centers and private practice. Health disparity related to screening without adequate options for access to health care is ethically untenable. Nurses are well positioned to reduce barriers to health care.
CHAPTER 1: BACKGROUND AND LITERATURE

Introduction

There is limited knowledge about women who enter the health system for a mammogram, have a finding requiring further follow-up and why they do not return for recommended health services. Studies suggest that a substantial number of women do not return for recommended care such as further diagnosis and treatment after breast abnormalities have been identified (Blackman & Masi, 2006; Kerner et al., 2003). Why women do not return for follow-up and if this problem is related to individual or organizational issues is not clear. Women who do not follow-up after an abnormality is identified through health screening are at risk for return to the health system with advanced disease. Later entry into the health system is likely to have both adverse personal and societal consequences.

Chapter one provides background information about the problem, and a review of the literature. Gaps in the literature are discussed. Use of health services after an abnormality is found through health screening is related to access to health care, a concept well studied in the United States. Literature related to access to health care is also presented as this helps to elucidate factors related to follow-up after health screening. The implications of this research for nursing, primary health care providers and for agencies that provide breast health care services are presented.

Background

In the United States, breast cancer is a significant problem, affecting approximately one in eight women (Blackman & Masi, 2006; Ries et al., 2005) and incidence is superseded only by cutaneous cancers. Invasive breast cancer is second only to lung cancer as a cause of cancer-
related death in women (Blackman & Masi, 2006; Ries et al., 2005; Lawson et al., 2000). It is generally accepted that early detection and treatment improves patient outcomes (Lauver et al., 2003; Nystrom et al., 2002). Mammography and clinical breast exam (CBE) remain the current recommendations for breast cancer detection, although the U.S. Preventive Task Force recommendations may lead to change. Currently, there is insufficient evidence to assess the additional benefit or harm of the CBE beyond screening mammography (2009). Identification by mammogram is usually one to three years before a lump is felt (American Cancer Society, 2007). Siqueira et al (2008) advocate clinical breast exam, ultrasound and mammography all contribute to tumor identification and all three should be used as complementary approaches to cancer detection. Due to focus upon early detection, research has targeted barriers to breast cancer screening. Less is known about the factors that may impede follow-up after an abnormality is found in women who have sought and accepted screening. It is also unclear if factors affecting follow-up on recommendations for health care are individual in nature or at the contextual health system level.

The health system in the United States is making efforts to decrease mortality associated with breast cancer. Interventions have included federal and state supported outreach efforts for breast cancer screening and follow-up after abnormalities are identified. In 1991, the Center for Disease Control (CDC) created the National Breast and Cervical Cancer Detection Program (NBCCEDP) to increase breast and cervical cancer screening among uninsured and low income women (Lawson et al., 2000).

For the first ten years, NBCCEDP provided only screening programs. While screening efforts are important, screening without treatment options creates marked health disparity.
Congress recognized this and in 2000, the Clinton administration signed the Breast and Cervical Cancer Prevention and Treatment Act of 2000, Public Law No. 106-354 (USDHHS, 2002) which allows states to extend Medicaid health insurance to uninsured women under the age of 65 who have been screened and diagnosed with either breast or cervical cancer through the NBCCEDP. In 2000, congress added $900 million over a 10 year period to the NBCCEDP program. In 2002, President Bush signed the Native American Breast and Cervical Cancer Treatment Technical Amendment Act of 2001, Public Law No. 107-121, to extend the same benefits to Native American women.

Breast care services through the NBCCEDP now includes medical history, cancer risk assessment, clinical breast exam, screening mammogram, diagnostic mammogram, ultrasound, biopsy, and referral to a surgeon (NBCCEDP website, 2009). Costs associated with these procedures will be covered by the NBCCEDP for eligible women. The NBCCEDP has also helped women overcome barriers to screening with transportation, child care, language and cultural considerations, provider referrals, and education, especially that addressing fear of cancer. Eligibility for this program includes women age 40 and older, who are uninsured or underinsured, meaning not covered by an insurance plan that will pay for breast screening, and have income at 100-250% of the federal poverty level which is $55,125 per year for a family of four (NBCCEDP website, 2010). NBCCEDP has joined state level efforts in all 50 states and is known as the Well Woman Health Check Program (WWHC) in Arizona.

Through the WWHC program, women may obtain services for breast or cervical abnormalities yet the program has limitations. First, there are far more eligible women than outreach and funding is able to accommodate, especially as the number of uninsured in the
United States continues to increase annually (Tanner, 2006). Second, federal guidelines mandate that only women who receive screening mammograms and/or initial diagnosis of breast cancer through NBCCEDP will have the benefits of financial coverage for follow-up care, diagnosis and treatment as well as case management services. Women who choose to pay for mammograms out of pocket or have screening through a program outside of the NBCCEDP would not be eligible for program services, even if they meet other inclusion guidelines. A diagnosis of abnormality has to be made through the NBCCEDP.

Programs offering breast cancer screening adhere to guidelines set forth by the Cancer Detection Section (2005) for follow-up care and follow the CDC mandate that women with abnormal mammograms attain a diagnosis within 60 days of screening. Results are classified according to the level of suspicion an abnormality is cancer. This classification is the Breast Imaging Reporting and Data System (BI-RADS) score (Table 1). Women with mammogram results in BI-RAD category 0, 3, 4, 5 have incomplete or abnormal results and are expected to have recommendations for follow-up care.

Multiple factors contribute to variation in the scope of the problem of lack of follow-up after breast cancer screening. The percentage of women who require follow-up after an incomplete or abnormal screening mammogram varies from 8.5-15% (Kerlikowske, et al, 2003) and as high as 37% (Wujcik, et al, 2009). Estimates of the number of women in the population who do not return after breast abnormalities are identified ranges from 8-23% in the state of Arizona. Estimates of delay for follow-up are higher in African American and Hispanic women (30-50%) (Arnsberger, et al, 2006; Gorin, et al, 2006; Kerner et al, 2003) and in women with anxiety (Blackman & Masi, 2006; Gorin et al., 2006; Kerner et al., 2003). Resolution is
reported from a few days to as high as one year for women who do return for follow-up, (Burack, et al, 2000). Delays of more than 90 days in women with symptomatic breast cancer are associated with increased recurrence and death (Richards et al, 1999).

It is difficult to conduct primary data collection studies on barriers to follow-up as it is difficult to find the women. Studies acknowledge the difficulty in gaining access to under-researched populations of women (Fair et al., 2009; DiMattio, 2001; Berg, 1999) and maintaining contact with women who do not return for follow-up diagnostic evaluation or treatment once a breast abnormality is identified (May et al., 2000). It is important not to assume that women who do not receive a final diagnosis are cancer free (May et al., 2000) or that lack of follow-up is an indication women have made well informed, personally satisfying decisions to forego further care.

**TABLE 1: BI-RADS Categories and Follow-up Recommendations.** Adapted from Breast Cancer Diagnostic Algorithms 3rd Ed (2005).

<table>
<thead>
<tr>
<th>BI-RAD 0</th>
<th>BI-RAD 1</th>
<th>BI-RAD 2</th>
<th>BI-RAD 3</th>
<th>BI-RAD 4</th>
<th>BI-RAD 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need comparison</td>
<td>Negative</td>
<td>Benign findings</td>
<td>Suspicious abnormality</td>
<td>Highly suggestive of malignancy</td>
<td>Known biopsy/proven malignancy</td>
</tr>
<tr>
<td>Additional imaging evaluation and/or mammogram needed</td>
<td>Usual screening schedule</td>
<td>Usual screening schedule</td>
<td>Biopsy should be considered</td>
<td>Appropriate action should be taken</td>
<td>Appropriate action should be taken</td>
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It is necessary to understand how women move through the health systems established to identify abnormalities, then diagnose and treat breast cancer, so those systems can improve care delivery and patient outcomes. Early diagnosis and treatment of breast cancer reduces both
personal consequences and financial costs. On the individual level, treatment of later stage disease is more extensive and prognosis for extended healthy life is diminished. On a health systems level, advanced breast cancers are more complicated and expensive to treat. If women do not follow-up for the recommended care such as further diagnostic tests, attain a diagnosis and start treatment for breast cancer, then determination of the points in time women depart from follow-up recommendations may help to identify where barriers exist.

**Literature Review**

Few studies have been conducted that focus on barriers to follow-up on recommendations for health care after an abnormality is identified during breast cancer screening. As early detection of breast cancer improves health outcomes, research has targeted barriers to breast cancer screening. It is unknown if the factors that contribute to barriers to screening are the same as those affecting follow-up on recommendations for health care after screening. The literature associated with breast cancer screening is presented briefly as studies related to follow-up have investigated some of the same factors.

**Breast Cancer Screening**

Studies indicate low socioeconomic status and being a member of a minority group are barriers to breast cancer screening (Loerzel & Busby, 2005; American Cancer Society, 2004; Sambamoorthi & McAlpine, 2003). The Center to Reduce Cancer Health Disparities (CRCHD) of the National Institutes of Health indicates overall low socioeconomic status is more influential than race or ethnicity on health seeking behaviors (2003). Lower income patients have lower five year relative survival rates than higher income patients at every stage of breast cancer (Bradley et al., 2001; Baquet & Commisky, 2000). Minority women are less likely to have medical insurance
and therefore, a regular source of care, both important factors as having a regular medical provider is a strong predictor of screening mammography (Blackman & Masi, 2006; Coughlin et al., 2004; Sambamoorthi & McAlpine, 2003; Williams et al., 2001). The uninsured and underinsured are less likely to receive preventive care in general and lack of health insurance is associated with more advanced stage of breast cancer at diagnosis (Andersen et al., 2007; Wyn & Solis, 2007; Atman & Taylor, 2001). The number of uninsured individuals in the United States is rising with more than 46 million people according to the U.S. Census Bureau (2005). Being an immigrant, living in the U.S. less than 10 years, and having less than a high school education are also identified as barriers to breast cancer screening (American Cancer Society, 2007; CDC, 2006).

Attitudes and beliefs are also identified as factors in breast cancer screening disparity (Lukwago et al., 2003). Negative attitudes and beliefs regarding breast cancer screening are found to be strong predictors for lack of mammography use (Weinick & Zuvekas, 2000). In a study of Hispanic and Black women, mammography use dropped 52-60% in those with negative cancer attitudes (Weinick & Zuvekas, 2000). Loerzel and Busby (2005) also found cultural beliefs and values have a role in health-seeking behaviors. They suggested Latina women are more fatalistic about the outcome of finding a cancer than other racial and ethnic groups, leading to avoidance of seeking screening.

Follow-up for Diagnostics and Treatment

A literature review of studies related to delay in follow-up for diagnostics and treatment after an abnormal mammogram was conducted (Appendix A). Criteria for inclusion in the review consisted of articles reporting on primary research in the last 10 years specifically pertaining to
follow-up after abnormal mammography. Disparity related to diagnosis and treatment is attributed to having delay in seeking symptom evaluation (Field et al., 2005; Lannin et al., 2002), delay in follow-up of abnormal mammogram (Gwyn et al., 2004; Kerner et al., 2003), and patient choice of treatment outside of accepted treatment guidelines (Li et al., 2003). Perceived lack of urgency, travel to appointments, special personal events, competing personal problems or demands, and anxiety have been found to contribute to delay in follow-up to abnormal mammograms (Gwyn et al., 2004; Kerner et al., 2003). Women who experienced delay in follow-up were less likely to have suspicious mammogram interpretation, and more likely to report cost of lost wages, cost of medical care and fears contributors to lack of follow-up (Rojas, et al., 1996). Patient choice of treatment for breast cancer that is outside of the evidenced based guidelines results in delays or lack of follow-up and has been found to be associated with lack of understanding, lack of communication or beliefs (Li et al., 2003).

A review of 22 descriptive retrospective studies addressing barriers to diagnostic resolution was recently summarized (Wujcik & Fair, 2008). Findings include women of non-white race without health insurance experienced more delay after incomplete or abnormal results. The reviewers found mostly patient barriers were described in the studies with little attention to provider or system categories.

African American women are found to have the greatest delays in diagnosis (Adams, et al., 2009, Chu et al., 2003) and delays in treatment for breast abnormalities (Gorin et al., 2006). This is important as African American women have higher incidence of breast cancer before age 40 (Ries et al., 2005). They are more likely to be diagnosed with larger and more aggressive
tumors (Ries et al., 2005). African American women are also more likely to die of breast cancer at every age (American Cancer Society, 2007).

Kerner et al. (2003), studied clinical follow-up among African American women with abnormal mammograms (n= 184), finding that 39.1% did not have diagnostic resolution of abnormal findings within three months and 27.7% did not have diagnostic resolution at six months. Chief contributing factors to follow-up care were found to include communication with health care professionals, severity of the diagnostic results, a prior history with breast abnormality, and anxiety. Communication factors affecting follow-up included being able to ask questions or receive instructions for the next step (Kerner et al., 2003; Poon et al., 2004). Women with a previous abnormal finding were less likely to follow-up in a timely manner (Kerner et al., 2003). African American women with anxiety were 50% less likely to obtain a cancer diagnosis within 90 days compared to those with lower anxiety scores (Kerner et al., 2003).

Whether or not follow-up after abnormal mammography is hampered by levels of anxiety or depression is not well studied, although the work of Kerner (2003) and others may indicate these factors warrant consideration. The literature does support that women report high levels of depression burden when diagnosed with cancer (Badger et al., 2007; Segrin et al., 2007; Sharpley & Christie, 2007; Burgess et al., 2005; Reddick et al., 2005). Research also suggests women undergoing cancer treatment should be assessed for depression (Badger, Braden & Mishel, 2001). A five year study in the UK involving 222 women indicated 50% of women with early breast cancer had depression, anxiety or both in the year surrounding diagnosis (Burgess et al., 2005). The study authors identified that longer term depression evolved from lack of a
confiding support person and the need for depression and anxiety services during the period of diagnosis and treatment. An Australian study of 197 breast cancer patients found participants had complaints of fatigue, feelings of loss of control and inability to cope which progressed to anxiety (Sharpley & Christie, 2007). The authors also found depression remained consistently related to an inability to cope or make decisions, feelings of helplessness, and loss (Sharpley & Christie, 2007). Fair et al. (2010) also found women with lower internal health locus of control were twice as likely as women with higher scores to have inadequate follow-up after abnormal mammography.

**Interventional Studies**

A literature review of interventional studies indicates further research to improve breast cancer screening, follow-up and treatment is needed. A Cochrane review of 22 studies focused on improving breast cancer screening reveals informed decision making, personalized risk assessment and communication had a small effect on increasing testing (Edwards et al., 2006). They found that there is insufficient data to report on other key outcomes such as intention to take the screening tests, anxiety, patient satisfaction with decisions, decisional conflict, knowledge and resource use (Edwards et al., 2006). Interventional research related to barriers to follow-up studied the effect of the role of a navigator for care. Battaglia et al. (2006) found 39% greater odds of timely follow-up with use of a patient navigator. Palmieri et el. (2009) found intervention by a nurse navigator shorted the time to diagnosis for 81% of participants.

In summary, barriers to cancer screening are multiple. Primary individual patient level barriers include low socioeconomic status, lack of health insurance, being an immigrant, living in the U.S. less than 10 years, less than a high school education, and being a member of a
racial/ethnic minority. Other individual level barriers include lack of a regular source of health care, lack of a regular health provider, cultural beliefs, negative perceptions of cancer, and fears associated with the tests or results.

The barriers to diagnosis and treatment include socio-economic factors, a perceived lack of urgency, severity of the results, previous history of breast abnormality, prior diagnosis of cancer, personal demands, travel, fear, anxiety, and low internal health locus of control. Other barriers to diagnosis and treatment identified in the literature include lack of knowledge concerning cancer, lack of communication, and making choices for treatment other than evidenced based guidelines. Review of the literature related to interventional studies indicates that while health care navigators may improve follow-up, further research is needed. Following is a discussion related to gaps in the literature.

**Gaps in the Literature**

There is clearly overlap in the breast cancer screening literature and the studies conducted so far on follow-up for recommendations for health care after screening. The primary gap in the literature is that factors identified as barriers to screening or follow-up are all at the individual level and there is a lack of investigation of factors at the organizational or health system level. Gaps in the breast cancer literature also include insufficient data to report on key outcomes such as intention to take screening tests, anxiety, patient decisional satisfaction, decisional conflict, knowledge and use of health care resources (Edwards et al., 2006). It is clear from this review of descriptive and interventional studies that not only individual level, but also organizational health system factors need to be included in studies related to follow-up after health screening. In order to understand potential barriers to follow-up after health screening it is important to turn
to literature at the health system level. The following is a review of that literature associated with access to health care.

**Access to Care**

The focal point of the problem described in this study is use of health services, or *access to health care*, a concept studied extensively in the U.S. Disparity in use of health services and patient outcomes is cause for concern and has given rise to two agencies: *Healthy People 2020* (HP 2020) and The Agency for Healthcare Research and Quality (AHRQ). These agencies gather annual reports of national progress toward resolution of health disparity and improvement in the health of the U.S. population.

The importance of conceptualizing and measuring access is the key to understanding and influencing health policy by predicting use of services, promoting social justice and improving effectiveness and efficiency of delivery (Andersen et al., 2007). Access to health care is defined in multiple ways. The Institute of Medicine (IOM) defines access as timely use of health services to achieve optimum health outcomes (IOM, 1993). Andersen and colleagues define access to care as the actual use of personal health services, all factors that facilitate or impede that use and the link between health service systems and the populations served (Andersen, 1998). HP 2020 aims to improve the health of our nation’s people. One of the overarching goals is to achieve health equity, eliminate disparities, and improve the health of all groups with *access to care* one of the primary objectives (USDHHS, 2009). AHRQ reports on measures of access to care in the Annual National Healthcare Disparities Report (NHDR). Measures of access to health care include assessments of how easily patients are able to get needed health services, use of services

Health disparity is defined as any differences among populations. The existence and persistence of health disparities between groups in the U.S. is well documented (AHRQ, 2009; HHS, 2004, 2005; IOM, 2003c; Kaiser Family Foundation, 2004). HP 2020 and NHDR reports emphasize the need for the U.S. to continue efforts to examine these phenomena. Through identification of individual factors and organizational factors that contribute to barriers to access to health care, health policy change can help to eradicate disparities. Barriers to access to health care comprise, but may not be limited to the individual and organizational factors listed in Table 2. Individual factors related to barriers to access to health care are similar to those reported in the breast cancer screening literature and include being a member of a racial or ethnic minority, lower socioeconomic status (AHRQ, 2009, 2006), the state of being uninsured or underinsured (AHRQ, 2009, 2006; Hadley, 2002; IOM, 2003a, 2003b; Tanne, 2006; USDHHS, 2005), not having an established facility of ongoing medical care (AHRQ, 2009, 2006; Starfield & Shi, 2004), not having a usual primary care provider with whom communication is effective (AHRQ, 2009, 2006), low health literacy (AHRQ, 2009, 2006), personal perceptions of delays or difficulties in getting care or other personal issues such as work demands, family responsibilities or fear (AHRQ, 2006; USDHHS, 2005).

Organizational factors that may constitute barriers to access to care may include lack of health facilities, location of health services, hours of operation, availability of public transportation; high costs associated with purchase of health insurance, high cost of health services when paying “out of pocket” (Himelhoch et al., 2004), timeliness or ability to get
services when needed, patient centeredness to include effective communication and accommodations for suboptimum health literacy (AHRQ, 2009, 2006); and health care utilization (USDHHS, 2005).

**TABLE 2: Barriers to Access to Health Care**

<table>
<thead>
<tr>
<th>Individual Factors</th>
<th>Organizational Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being a member of a racial or ethnic minority **</td>
<td>Lack of health facilities</td>
</tr>
<tr>
<td>Personal issues such as work demands, family responsibilities or fear</td>
<td>Location of health services</td>
</tr>
<tr>
<td>Lower socioeconomic status</td>
<td>Health facility hours of operation</td>
</tr>
<tr>
<td>The state of being uninsured or underinsured **</td>
<td>Availability of public transportation</td>
</tr>
<tr>
<td>Not having an established facility of ongoing medical care</td>
<td>High costs associated with purchase of health insurance</td>
</tr>
<tr>
<td>Not having a usual primary care provider with whom communication is effective</td>
<td>High cost of health services when paying “out of pocket”</td>
</tr>
<tr>
<td>Low health literacy **</td>
<td>Timeliness or ability to get services when needed</td>
</tr>
<tr>
<td>Personal perceptions of delays or difficulties in getting care</td>
<td>Patient centeredness to include effective communication with provider and others</td>
</tr>
<tr>
<td>Primary language other than English**</td>
<td>Health care utilization</td>
</tr>
</tbody>
</table>

**May constitute individual and organizational factors**

Several of the factors identified at the individual level may also constitute organizational level issues. For example, being a member of a racial or ethnic minority, low health literacy or being non English speaking could transfer into organizational level issues if facilities do not employ multicultural providers and staff, do not take the time necessary to work with individuals with low health literacy or take no measures to employ interpreters. Likewise, being uninsured may also translate into an organizational level barrier to access if a health clinic does not offer
sliding scale fees, or discounts on lab and pharmacy. The state of being uninsured is an
overriding element of barriers to health care access. The uninsured are more likely to live in
states of poorer health and to die earlier than expected (AHRQ, 2009, 2006). The financial
burden of being uninsured is substantial at the individual level and at society level. A major
reason for personal bankruptcy filings are due to medical expenses (IOM, 2003a) and the costs of
eyearly death and poor health among the uninsured total billions of dollars annually (AHRQ, 2009,
2006).

In summary, the phenomenon of women who demonstrate concern for health and
acceptance of a mammogram, but do not follow through with care when abnormalities are
identified, is complex and produces both individual level and health system level questions. A
review of the literature indicates the barriers to screening may inform the problem of barriers to
follow-up after abnormalities are identified. While there are few studies related to follow-up
after abnormal mammography, those that are in the literature represent individual factors and less
consideration of factors at the health system level. Determination of the effects of varied
individual characteristics, as well as differing organizational contexts of health care delivery
must also be considered.

**Problem and Significance**

There is limited knowledge about women who enter the health system for mammograms,
have an abnormal finding requiring further diagnostic tests and possible treatment of breast
cancer, and the contextual and individual characteristics associated with use of recommended
health services. Lack of return for follow-up services after abnormal screening may constitute
delayed treatment and poorer health outcomes. Delayed treatment may result in later entry into
the health care system with advanced stage disease. The effect of a later stage of disease may then be more extensive and expensive cancer care once the individual reenters the health system, thus burdening societal resources. Late stage cancerous breast disease likely results in less favorable health outcomes or early death.

**Statement of Purpose, Aims and Research Questions**

The purpose of this research is to describe contextual characteristics at the health delivery level as well as individual characteristics of women with abnormal mammography, and their association with use of follow-up health services. Particularly, this research examines the differences between women who are early and late responders after an abnormal mammogram.

The overarching question of this study is whether or not there is an association between contextual characteristics and individual characteristics of women with abnormal mammograms and follow-up on recommendations for health care after health screening. The following three aims of this study and corresponding research questions are written to answer this overarching question.

Aim 1: To describe the contextual characteristics of the agencies and locations served by the mobile mammography units and the relationships with use of health services in women with abnormal mammograms.

Question 1: What are the relationships between contextual characteristics and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

Aim 2: To describe individual characteristics and the relationships with use of health services in women with abnormal mammograms.
Question 2: What are the relationships between predisposing characteristics and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

Question 3: What are the relationships between enabling characteristics and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

Question 4: What are the relationships between characteristics pertaining to perceived needs and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

Aim 3: To describe satisfaction with health care and the relationships with use of health services in women with abnormal mammograms.

Question 5: Is there a relationship between satisfaction with the most recent specific event of health care and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

Question 6: What are the relationships between satisfaction with previous health care services in general and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

Question 7: To what extent did women follow recommendations for care within 14 days of notification of an abnormal mammogram?

Significance to Nursing

Historically, the study of access to health care and the relationship to health disparities among vulnerable citizens in the U.S. has crossed professional disciplines. Nursing studies of
health disparities have provided valuable contributions to advance nursing knowledge related to health disparities (Flaskerud et al., 2002). Health services researchers have contributed sentinel works related to access and health care utilization (Aday & Andersen, 1974, 1981; Andersen, 1995; Phillips et al., 1998). Andersen, Aday and colleagues have also contributed important work to understanding the relationships between access to health care, equity in health services distribution and the implications for social policy development (Andersen, 2007).

This study explored access to health care in women by observing the association with use of health services after health screening. This study has potential implications for delivery of health services, development of interventions to influence practice, and health policy. Potential health care delivery implications include risk recognition for non-completion of care, greater efficiency and cost effectiveness. Possible health care practice implications include development of interventions to remove barriers to follow-up after health screening and improve patient outcomes. Studies with focus upon improvement in organizational processes to facilitate access to care have possible implications for other health screening programs, community health centers and health policy.

Summary

Breast cancer is the most common malignancy among women in the United States with the exception of skin cancer. There is a lack of knowledge about women who do not follow-up for recommended health care after abnormal mammograms. The known barriers to access to health care are many, with low socio economic status and insurance figuring prominently in the ability to obtain health care. However, less is known about the individual characteristics of
women who choose not to return for follow-up care and the organizational health system level factors that may be barriers to follow-up.

While implementation of national policy to ensure federal health insurance for women with a diagnosis of breast cancer through the NBCCEDP and state programs would seem to be an ameliorating factor, problems persist. In fact, inadequate identification of these women may result in delayed treatment and poorer health outcomes. Delayed treatment may result in advanced stage disease which is more extensive and expensive to treat. Late stage cancerous breast disease also likely results in less favorable health outcomes or early death. The aims of this study include examination of contextual characteristics of the setting in which women receive breast cancer screening, the individual characteristics of the women including previous satisfaction with experiences in the medical system, and association with use of services after abnormal mammography.

The literature suggests there are many parallels in health disparity indicators at the individual and organizational level found when comparing breast cancer literature with literature from studies disseminated by HP 2020 and the NHDR. Gaps in the literature are found related to interventions to improve access to health care and eliminate health disparity. These gaps hold implications for future studies in women with barriers to follow-up after identification of abnormalities through health screening.
CHAPTER 2: CONCEPTUAL PERSPECTIVE

Introduction

The Model of Use of Health Services is the conceptual framework for this study. The model serves to explain access to health care and helps to differentiate between access that represents health disparity or health equity. The relationship of the theoretical underpinnings of the model related to nursing is explained. The variables specific to this study will be presented and the relationship to the model will be discussed.

Conceptual Model

The conceptual model guiding this research study (Figure 1) is an adaptation of the Behavioral Model (Andersen et al., 2007). Andersen describes use of health services as access to care and the model has been used extensively in research predicting use of health services in efforts to promote social justice and improve effectiveness and efficiency of health care delivery (Andersen et al., 2007). Questions associated with access to health care span multiple populations and the model is adaptable to many populations and questions.

Philosophical Underpinnings of the Model

The cardinal principles of medical ethics include autonomy, beneficence, and justice. These principles are all considered important to public health with justice at the core (Rosenau and Roemer in Andersen, 2007). Public health is social justice; whether defined as equality of opportunity, equity of access or equity of benefits. Equity is defined as the extent health disparities or inequalities persist among groups (Aday et al., 2001). Public health is concerned with vulnerable populations, equity among social groups, compensation for suffering and surveillance of the total health system (Rosenau & Roemer in Andersen, 2007). Ethics and
 justice is the philosophy that underpins the work related to access to health care and the Model of Use of Health Services. The model was formed on the imperative for assessment and improvement in access to care.

**Equity and Health of Women**

Study of use of health services has led Andersen and colleagues to draw important conclusions between access to care and equity (Aday & Andersen, 1981; Aday et al., 2001). Equity is defined as the extent health disparities or inequalities persist among groups (Aday et al., 2001). Access to care is a complex measure. Whether access is equitable or inequitable depends upon the dominant predictors of realized access (Andersen, 1995). In the model, for example, demographic characteristics such as age and gender as well as need are primary determinants of use of health services in equitable access (Andersen, 1995). If social structure indicators such as ethnicity, health beliefs and enabling resources like income are the primary determinants of use of care then it would constitute inequitable access (Andersen, 1995).

Aday provides insight into a systems approach to study access to health care incorporating both individual and organizational or community factors. Many of the constructs and indicators associated with her equity model are reflected in those currently being tracked by assessments in HP 2020 and the AHRQ’s disparity report. Mulhall and Swift (1992) note the distinctions between individual and community perspectives (as in Aday et al., 2001). They point out individual rights frequently make their way into discussions of barriers to access to care while community level values based on norms of the common good may be used to counter such claims (Aday et al., 2001). Aday outlines a framework for studying equity in health care that clearly delineates three sides of this debate of equity: distributive justice, social justice and
deliberative justice. According to Aday (2001), health policy influences the health delivery system and who it serves at the federal, state and local levels. Aday expresses that the deliberative justice character of health policy conveys that conflicts between the disparate paradigms of distributive justice and social justice that have tended to guide medical care and public health policy in the U.S. must be effectively resolved if well being of individuals and communities is to be realized (Aday et al., 2001).

Aday states the goal of health policy should be to contribute to improving the health of individuals and communities (2001). She explains there is a reciprocal relationship between access to care and health disparities. Access to care and disparity each influence the other and both lead to effectiveness of health care delivery. Effectiveness of health care delivery impacts
both equity and efficiency with health and well being of individuals and communities as the primary explicit outcome. The conceptualization and measurement of access to health care is considered key to understanding and formulation of health policy because both can be used to understand health service use and to promote equity, effectiveness and efficiency of that use (Aday et al., 1993; Andersen, 1998).

There are multiple issues associated with health status, socioeconomic status and multiple role responsibilities that affect access to and use of health services for women (Wyn & Solis, 2007; Andersen et al., 2007). Women have lower insured rates and higher utilization of services than men. Many health concerns are particular to women, and occur with greater frequency. Women have more limited health insurance options and large discrepancies among women in coverage rate and health care use according to income, education and ethnicity. It has also been found that after women gain access to the health system, there is greater differential in procedures and outcomes than men (Wyn & Solis, 2007; Andersen et al., 2007). In addition, women have the lower rates for screening for certain clinically preventive services and are most vulnerable to the effects of cost (Wyn & Solis, 2007).

**Model and Study Variables**

Adaptation of the Model of Use of Health Services for use in this study is influenced by work done with rural populations (Ferketich, Phillips, Verran, 1990, 1993) and urban groups (Badger et al., 2000). The variables chosen from the model for this adaptation are those reflected in the literature as most pertinent to use of health services. The variables for this study include contextual characteristics of the setting, individual characteristics and the outcome of use of health services.
Contextual Characteristics

Contextual characteristics are the circumstances and environment of health care access and are comprised of predisposing, enabling and need variables. In this study, only enabling organizational factors will be included. Organization is the amount and distribution of health facilities and personnel, the structure to offer services, supply of services to the community, as well as the organization of care.

The pertinent organizational enabling characteristics in this study will serve as descriptors of the setting in which study participants receive care and include those related to the organizational program services and staff. Organizational program services include geographic service range of each facility, distances to sites for diagnostics and treatment, availability of public transportation, outreach activities, and structure for screening such as clinical breast exams and education. Organizational characteristics related to staff include number and composition of staff by gender, ethnicity, and languages spoken, as well as case management and support staff structure. While other contextual characteristics describing predisposing factors, enabling characteristics and need, are important aspects of the conceptual framework, they are beyond the scope of this study at this time.

Individual Characteristics

Individual characteristics of the Model of Use of Health Services are also comprised of predisposing, enabling and need factors. Individual characteristics differ from variables at the contextual level because the focus is narrowed from the wider community to the individual. Predisposing factors include demographics, social status and beliefs. Enabling characteristics include finance and access to care. Perceived Needs include status and health patterns.
Satisfaction is specific for the last health visit and in general for mammograms and health visits. The outcome is use of health services, which is defined as the time from notification of abnormal results to the first follow-up appointment.

**Definition of Terms**

Following is a definition of terms for use in this study. Examples are given of each of the terms as they relate to the variables in the Model of Use of Health Services.

**Contextual characteristics:** Characteristics of the organizations providing breast cancer screening and managing follow-up care.

**Individual characteristics:** A broad term referring to predisposing, enabling, need and satisfaction factors that contribute to health care access at the individual level. Individual characteristics differ from variables at the contextual level as the focus is narrowed from the wider community to the individual or family.

**Predisposing individual characteristics:** Personal existing conditions including demographics, social status and beliefs.

- **Demographics (individual):** Characteristics associated with a likelihood of people needing health services. Examples include age, family history of cancer, previous abnormal mammogram, and previous cancer.

- **Social status (individual):** Characteristics of the person within the community, ability to cope with health problems, ability to command resources to deal with problems. Examples include education, literacy, work status, marital status, and perceived support.
• **Beliefs (individual)**: Characteristics that influence perceptions of need and use of health services. Examples include value of health care, attitudes toward use of health care, and fears.

**Enabling individual characteristics**: Characteristics that facilitate use of health services at the individual level. Enabling characteristics include finance and access to care.

• **Finance (individual)**: Resources available to pay for health services; cost of health services. Examples include household financial status, insurance status, out of pocket costs, perception of ability to get financial assistance if needed.

• **Access (individual)**: Transportation for health care.

**Perceived Needs**: Perceptions of what is needed for health care or what may influence health care.

• **Status (individual)**: Personal status. Examples include presence of breast symptoms, anxiety, depression, and overall health.

• **Patterns (individual)**: Patterns of health. Examples include past follow-up pattern and preventive pattern.

**Satisfaction**: How individuals feel about the health care they received.

• **Specific (individual)**: Satisfaction with a specific health care event. Example includes satisfaction with the last health visit.

• **General (individual)**: Satisfaction with health care in general. Examples include satisfactions with mammograms and health visits in general.
**Outcome: Use of personal health services:** A term that describes access to health care:

An example of use in this study is follow-up for recommended health care after abnormal mammograms.

**Summary**

In this chapter, The Model of Use of Health Services was presented as the conceptual framework for this study. The model considers contextual characteristics of the setting in which women receive screening and management of follow-up care. The model also considers individual characteristics of the women themselves to include predisposing and enabling factors, perceived needs, and satisfaction. Use of health services is depicted as the outcome in the model. Chapter three will present the study design and methods.
CHAPTER 3: METHODS

Introduction

Chapter two presented the conceptual perspective that contextual and individual characteristics were associated with use of health services. These characteristics were explored to determine if there was a relationship with follow-up on recommendations for health care in a population of women with abnormal mammograms. Contextual characteristics included geographic location, agency programs and staff. Individual characteristics included predisposing and enabling factors, perceived needs, and satisfaction with health care. Chapter three describes data collection procedures and methods for conducting analysis.

Study Design

This descriptive study was designed to gather individual level data and analyze the relationship with follow-up on recommendations for health care after abnormal mammogram in a convenience sample of women. Individual characteristics were gathered using the Survey of Health Status and Health Needs (SHSHN) and the Hospital Anxiety and Depression Survey (HADS) (Appendix B). Surveys were distributed to interested participants during breast cancer screening mobile mammogram events. Concurrent chart reviews were conducted of women with mammogram results in the Breast Imaging Reporting and Data System (BIRADS) 0, 3, 4, or 5 categories. These categories indicated a need for further diagnostic tests and possibly treatment for breast cancer. Data gathered on the women’s follow-up patterns were accessed from medical records at the state agency of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), or the associated medical facility. Chart review concluded when a participant’s recommended care was complete; the chart review period had reached 90 days; or the
participant’s case was closed by the agency due to withdrawal from the program, noncompliance with recommendations, or death.

**Setting**

The setting for sample recruitment and data collection was multiple mobile mammogram screening events in urban and rural Arizona. Urban and rural agencies of the NBCCEDP sponsored the mobile mammogram screening events either alone or in collaboration with community partners. Community partners included private medical offices, clinics, church groups, schools and others. Two women’s groups, activists in promoting breast cancer outreach and education, were instrumental in funding the presence of the mobile mammogram units at many of the events. The intent was to reach underserved, uninsured, women; many without previous mammograms. The partners assisted in coordination, staffed the events, and promoted screening within the communities using TV, radio, newspaper, and fliers. They also arranged educational activities at the events to promote breast health.

Mobile mammogram screening events were conducive to ease of access, ready availability, timing, size of the convenience sample, and access to medical records. Women could easily access the events as they took place in their home communities. Women pre-registered through the sponsoring agency, phone reservations through community postings in the newspaper, TV or internet, or could simply approach the mobile mammogram unit on the day of screening. Whether pre-registered or simply showing up on the day of screening, all women received an overview of the NBCCEDP scope of services and income qualifications in their primary language.
The mammograms were readily available to women as there was no need for prior orders or medical appointments. Mammogram screenings were free of charge as long as women met criteria for participation, and were therefore, popular. The time women spent waiting for registration and screening with the mobile unit was conducive to completion of the survey. The survey was offered while women waited their turn for mammograms, providing expediency to the flow, yet ample time so data collection was not rushed.

The mobile screening events were chosen to increase the size of the convenience sample over other forms of screening where women are cared for individually. While the number of women screened at each event was expected to vary, mobile mammogram events constituted the only gathering of groups of women for screening at one time.

Lastly, data collection through NBCCEDP sponsored events ensured the ability to gain access to medical records of participants who had abnormal results of the screening mammograms. Data collection, by chart review for women with abnormal results, took place in the designated NBCCEDP program offices, medical offices or clinics associated with the individual participants.

**Sample**

Participants were a convenience sample of women who chose to participate in mobile breast cancer screening. Target sample size was 400 women, a number found to be adequate to eliminate subject variance when evaluating instrument reliability and validity and sufficient to provide an adequate number of women in the subgroup with BIRAD 0, 2, 3, 4, or 5 mammogram results. National statistics indicate 10-15% of women undergoing screening mammography have abnormal or incomplete findings requiring further studies (Wujcik & Fair, 2008). It was
estimated approximately 10% of women screened through the mobile unit would have mammogram results in one of the BIRAD categories above, providing 40 cases to follow by chart review.

Inclusion criteria were female gender, age 18 or older, English or Spanish speaking, and residence in a participating geographic area of Arizona. While the recommended age for annual screening at the time of data collection was age 40 (ACS, 2007), studies indicated younger women have need for breast cancer screening also. This is often due to positive family history for breast cancer or suspected abnormality (Ries et al., 2005), so women younger than 40 years were included in the study. Criteria for exclusion were prisoner status or the state of being homeless.

**Procedures**

Presentation of data collection procedures describes the sequence of significant events in the planning and implementation of the research and facilitates replication of the study. In this section, human subject’s protection and sample recruitment are discussed; specific information given to the participants is presented; and consent, data collection and data entry procedures are reviewed.

The literature supports specific procedures in the study design to assist in recruitment of participants (Berg, 1999; DiMattio, 2001) and sensitivity to rural considerations for privacy and cultural norms (Ferketich, Phillips & Verran, 1993). The procedures used in research with similar populations to those in this study, included obtaining the support of agency and community leaders; advertising in community publications; and utilizing age, gender, language and culturally matched members of the research team to interact with participants in the
recruitment process. Research with similar populations also included mindfulness that small community members prefer a level of anonymity associated with survey completion that may be difficult to obtain if “insiders” participate in gathering data. The importance of respect and accommodation for close familial ties present in many cultures also shaped procedures for this study. All of these points were incorporated into the procedures for this study. Some have already been discussed in the setting and sample, the remaining elements of the study procedures are discussed below.

**Collaborative Partnerships**

Development of collaborative partnerships was integral to access to the population of underserved women involved in this study. The problem of lack of follow-up to complete recommendations for medical diagnostics and treatment after women have an abnormal finding on mammogram was well recognized by the collaborative partners. Study approval from the NBCCEDP was obtained through the state level office of Well Woman Health Check, a division of Arizona Department of Human Services. With this support, decisions about sites for data collection were made based upon whether or not a program used mobile mammography services, and the number of women served in the region annually.

Following site selection, meetings with regional program managers were scheduled to further develop collaborative relationships. Permission was sought and obtained from the managers to collect data at screening events in their regions. Since some of the agencies also partnered with individual health offices, clinics, and groups, meetings were also conducted with these key individuals. Likewise, permission was obtained from them to conduct data collection
during the breast cancer screening events. All collaborative partners wrote letters of support and agreement and these were incorporated into the Institutional Review Board application.

**Research Assistants**

Three bilingual research assistants (RAs), fluent in Spanish, and of Hispanic descent, were trained in the study procedures. The RAs resided in regions proximal to the screening events, but not within the communities being researched, so anonymity for participants was preserved. All RAs were Baccalaureate Nursing students and had completed research course work. All RAs satisfactorily completed the Collaborative Institutional Training Initiative (CITI) online course for human subject’s protection.

**Human Subjects and Sample Recruitment**

Human subject’s procedures ensure protection of privacy and clearly outline how the information gathered from participants will be used. Approval from the Human Subject’s Protection Program and the University of Arizona was sought and approved (Appendix C). Once institutional review board approval was obtained, data collection at screening events began.

All screening of participants was provided by the mobile mammogram unit, so this was the focal point of the setting for recruitment of participants into the study. The primary investigator (PI) and a bilingual RA provided a table with flyers describing the study in close proximity to the mobile mammogram van. Written information was available in English and Spanish. The PI and RA were present to provide informed consent and answer questions. Refreshments and shade were available for the women. Chairs were spaced appropriately for privacy and provided a place for participants to sit while completing the survey.
Information about the Study

Women who approached the table set up by the PI and RA were given a flier and the study was explained. Potential participants were told the purpose of the study was to find out how women moved through the health system for a mammogram and the follow-up health care that might be needed if the results of the mammogram were abnormal. Potential participants were told if they agreed to be in the study, their progress would be followed through the health system by review of their medical record for a period of time until resolution of the follow-up health care needed, or for 90 days. If they agreed to be in the study, they would complete a survey of their personal health status and health needs in English or Spanish, requiring approximately 15 minutes. The PI and RA would be present to help with questions or translation during the survey.

Participants were informed risks of participation in the study might include loss of confidentiality and perhaps feeling uncomfortable answering some of the questions. Participants were assured measures were in place to protect participant confidentiality: names would not be used in any reports or publications, no audio or video recordings were made, and participants could stop the survey at any time. While there were no direct benefits of being in the survey, including no financial gains, participants were told the study information may help medical persons plan better care for other women being screened or treated for breast cancer. Participants were also assured of no change in their ability to get health care by either participating or not participating in the study. Family members were included in the study explanation, encouraged to ask questions, or to sit with the participants, if the participants so
desired. Women, who agreed, proceeded to the informed consent process and retained the flyer for reference.

**Informed Consent and HIPAA Waiver**

Informed consent was obtained for all interested women who met inclusion criteria and agreed to participation. The PI or bilingual research assistant provided the consent (Appendix D) to the potential participant in face-to-face encounters and the participant was given a copy of the consent form in either English or Spanish.

A Health Information Portability and Accountability Act (HIPAA) waiver was presented to obtain permission to access the medical record for chart review purposes. The HIPAA form (Appendix E) outlined what specific information would be extracted from the medical record including mammogram and other associated results, follow-up care recommended, care received, and contacts by agencies involved in care. Participants were also given a copy of the HIPAA consent.

**Data Collection**

Once participants completed the informed consent and HIPAA waiver process, they entered identifying information into a log and were assigned study identification numbers. These numbers were placed on the surveys. The participants were given clipboards, pens, and the numbered SHSHN and HADS. Women returned to the seating area to complete the survey. It was expected participants would take between 15 and 30 minutes to complete the two surveys. Women returned to the table with the surveys when finished. The surveys were checked for completeness and filed. Participants were given a small token of appreciation for their time by way of a lapel pin and thanked for participating.
**Outcome Data Collection by Chart Review**

Within fourteen days after the screening date, the PI contacted the Well Woman Health Check administrator to obtain mammogram results of participants. If results were negative (BIRAD 1 or 2), no further follow up was necessary. Women with incomplete or abnormal results (BIRAD 0, 3, 4, 5) were followed further with chart reviews. Chart reviews were conducted in the designated agency office. The chart reviews included medical orders for follow-up care, case notes related to participant notification of results, recommendations for follow-up, and the care received. Chart reviews concluded when the recommended care was complete; the chart review period had reached 90 days; or the participant’s case was closed by the agency due to withdrawal from the program, noncompliance with recommendations, or death.

**Data Entry**

Data entry procedures included de-identification of participant information, data entry and database development. The PI completed all data entry after data collection. All survey data were de-identified with use of the study numbers assigned at data collection. All data were entered into a password protected computer and analysis program by the PI. The linkage documents (identifying information on the top page of the surveys) were removed and stored separately from the survey. Both were stored in a locked file cabinet in the PI’s office. Due to the large size of the two surveys, a data entry program was created in Microsoft Access. This method of data entry utilized dropdown text for ease and reduction of errors. The program simultaneously converted all entries to a database, which was later converted to SPSS 17, the preferred program for analysis. Consents and HIPAA forms were managed in accordance with IRB procedures to include storage in the College of Nursing, University of Arizona.
Instruments

The instruments used in this study were the Survey of Health Status and Health Needs (SHSHN) and the Hospital Anxiety and Depression Survey (HADS). The following is a detailed description of both instruments including past use, psychometrics and an explanation of the survey questions.

Survey of Health Status and Health Needs

The SHSHN is a survey based upon the Behavioral Model (Aday & Andersen, 1975; Andersen et al., 1981). The SHSHN was originally developed to study multi-level nursing practice models for rural Hispanics (Ferketich, Phillips & Verran, 1990, 1993). The instrument was also used to study urban dwelling, medically underserved populations (Badger et al., 2000, 2001). The SHSHN instrument has been used in large cross-cultural community samples with good reliability of subscales reported in rural populations (alpha .87-.91) (Ferketich, Phillips & Verran, 1990, 1993). The SHSHN demonstrated good reliability in urban populations (alpha .46-.97) with the exception of mental health services (.46) (Badger et al., 2000). Previous testing of the instrument demonstrated high construct validity (CFI .95-.98) (Ferketich, Phillips & Verran, 1990, 1993).

Availability of the instrument in both English and Spanish made it possible for participants to answer the questions in the language of primary use. The survey was translated from English into Spanish, and then double back-translated to ensure appropriateness for use. The Spanish survey was double sided with the questions in English on the alternate side for participants who may benefit from moving between both languages.
The SHSHN was used to gather data on individual characteristics and health outcomes. The survey contained five categories including personal information, health service availability, health service needs, health care acceptance, and outcomes. The following sections describe the survey questions and how the variables were measured. Explanation regarding composite computations made for some of the variables is also provided.

**Personal Information**

Personal information involved 23 questions about demographics, social status, beliefs, and financial perspectives. Demographics included questions related to age, family history of cancer, previous abnormal mammograms, and previous cancer. Social questions involved education, literacy, employment, marital status, and social support. Beliefs included worries or fears related to health, tests or procedures, and costs or how to pay for health care. Questions related to finance addressed insurance status, monthly out of pocket costs, and if participants perceived the ability to get financial assistance for medical care if diagnosed with breast cancer. Participants were also asked to rate the household financial status in one of four categories ranging from “does not have enough money to pay bills” to “have enough money to do whatever we want.” Measurement of some of these questions was at the nominal level with dichotomous answers of “yes/ no”. Ranked answers such as household finance and out of pocket expenses were measured at the ordinal level. Age was a continuous variable measured at the interval level.

**Health Service Availability**

Health Service Availability contained three questions about participants’ opinions on use of professional health care, availability of transportation, and conditions that prompted a
need for health care. The question related to use of professional health care was a dichotomous “yes/ no” answer and asked if it was sought only when family and friends could not provide the help needed. These answers were considered attitudes toward health care and were measured at the nominal level. The transportation question asked participants to rank ease of access to transportation for health care from “very easy” to “very difficult.” These answers were measured at the ordinal level. The question related to conditions prompting a need for health care contained 27 items and asked which would require prompt health care service. The items were scored zero for “no” and one for “yes,” summed, then analyzed using factor analysis. Factors would be interpreted as the higher the score, the more value of health care and were measured at the interval level.

Health Service Needs

Health Service Needs was comprised of three questions related to presence of breast symptoms; current overall health; and use of health services in the last year. The first question addressed any current breast symptoms with answers being dichotomous, “yes”/ “no”, and measured at the ordinal level. Current health status was a narrative question asking “how is your health.” The last question regarding use of health services contained 10 items pertaining to screening tests obtained in the past year. These tests would be expected of participants in this age range receiving recommended levels of health care and answers were dichotomous, “yes/ no”. The items were summed, then divided by ten to transform to the percentage of screening tests in the past year. This question pertained to the participants’ preventive patterns, was scored 0.00- 1.00, with the higher the score, the more preventive care participants received in the past year. Preventive pattern was measured at the interval level.
Health Care Acceptance

Health Care Acceptance included four questions related to follow-up patterns and a Likert scale question about specific satisfaction with the last health visit. Past Follow-up Pattern is an indicator of the past follow-up recommended by the participant’s health provider such as additional tests, medications, or lifestyle changes and the response to those recommendations. Women answered narrative questions of “Did your health care provider recommend any screening tests?” “Did your provider recommend any action due to results of the tests?” What did your provider ask you to do?” “What did you do about the recommendations?” From the narrative, answers were ranked as “no recommendations,” “had recommended follow-up” or “did not have recommended follow-up” and were measured at the ordinal level.

Satisfaction with the last health visit was a five point Likert scale of 14 items rated from 1: “very happy” to 5: “very unhappy.” The items gathered data on specific markers of quality associated with the provider-patient relationship at the last health visit such as amount of time to get the appointment; amount of time it took to get there; the time and attention the provider spent listening to complaints, opinions, and fears; education given; cost; respect shown; communication; and the visit overall. Data were measured at the interval level. Data pertaining to each item of satisfaction with the last health visit were summed: scores ranged from 14 indicating “very happy” to 70 “very unhappy” with aspects of the last visit. The scores were then divided by 14 to transform to a mean score ranging from 1.00-5.00. This variable was labeled Specific Event Satisfaction: Last Health Visit and interpretation included more
satisfaction with the last health visit with scores closer to 1.00, and higher scores indicated less satisfaction.

**Outcomes**

Outcomes had four questions related to satisfaction, overall health status and current personal perceptions of health. Satisfaction items gathered data on general satisfaction with past mammograms and health visits. These satisfaction questions differed from Specific Event Satisfaction: Last Health Visit in that the focus was broad and included more than the provider-patient relationship. Items included cost; quality; availability; convenience; length of wait for appointments; helpfulness; friendliness; individual attention; patience, not feeling rushed; genuine interest shown; and cultural sensitivity. These eleven items for general satisfaction with mammograms and visits were both five point Likert scales rated from 1: “very happy” to 5: “very unhappy.” Scores were derived for both satisfaction variables with the same process as Specific Event Satisfaction: Last Health Visit. Mean scores for General Health Care Satisfaction: Mammograms and General Health Care Satisfaction: Health Visits likewise ranged from 1.00- 5.00 with scores closer to 1.00 indicating higher satisfaction, and higher scores indicating less satisfaction. Measurement of general satisfaction was at the interval level.

The question of overall health status asked participants to rank how healthy they were right now on five points ranging from “extremely” to “not at all.” Measurement for overall health status was at the interval level. Narrative questions asked about the meaning of health, what participants might change about the health care they were receiving now and any additional comments about health care or services needed or available. Narrative answers were considered at the string level.
The Hospital Anxiety and Depression Survey

The Hospital Anxiety and Depression Survey (HADS) is a tool used to evaluate levels of anxiety and/or depression (Snaith, 2003). The HADS is well supported in the literature as a tool to evaluate both anxiety and depression (Hahn, Reuter & Harter, 2006; Caci et al., 2003; Montazeri et al., 2003; Snaith, 2003;) and in women with breast cancer (Montazeri et al., 2003). Previous testing of the HADS found it reliable and valid for use in women with breast cancer: anxiety subscale (r .47-.83) and depression subscale (r .48-.86) (Montazeri et al., 2003).

The HADS is a 14 item instrument with seven items pertaining to anxiety and seven items related to depression. Each item uses a four point Likert response scale. Items were scored 0 (no anxiety or depression) to 4 (severe), then summed, to produce an anxiety and depression score ranging from 0-28 for each variable. Both anxiety and depression were measured at the interval level. Interpretation of the scores included the higher the score, the more anxiety or depression.

Data Analysis

The full sample of women in this study was divided and data were analyzed for the subset of women with normal results and for the subset of women with abnormal mammograms. Exploratory data analysis, reliability (alpha) and construct validity (Factor Analysis) were completed on the full data set. Analysis of the subset of women with abnormal mammogram was integral to answering research questions. The research questions explored the associations between contextual characteristics of the screening environment and individual characteristics with follow-up on recommendations for health care after screening in the subset
of women with abnormal mammograms. A significance level of 0.1 or better was considered acceptable due to the exploratory nature of this research.

Kendall’s Tau correlation coefficient was used to analyze the data of women with abnormal mammograms. Correlation was used to measure the linear relationship between independent variables and the outcome variable: Mean Time from Results Notification to First Follow-up Appointment.

Summary

This study included a descriptive design with quantitative data collection through participant survey at breast cancer screening events in two counties and multiple sites through agencies and collaborating partners in urban and rural Arizona. The survey instruments included the SHSHN and HADS. Data were gathered to include contextual characteristics of the settings in which women received screening, individual characteristics of the women themselves, and outcomes related to use of health services. Chart reviews were conducted for women with screening mammograms in BIRAD categories 0, 2, 3, 4, or 5. These participants had needs for additional health care including diagnostics and possibly treatment for breast cancer. Analysis involved Kendall’s correlation coefficients with the outcome variable: time to first follow-up appointment for recommended health care in women with abnormal mammograms.
CHAPTER 4: RESULTS

Introduction

Chapter four presents the results of data collection and analysis. Contextual characteristics of the multiple settings where the mobile mammography unit screened women for breast cancer are also presented. Demographics are presented for both the larger group of women screened with normal mammography (n = 349) and the subgroup of women with abnormal mammography (n = 31). The results of instrument reliability and validity are presented. The results of analysis of contextual and individual characteristics and relationship with the time to first follow-up appointment for recommended health care in women with abnormal mammograms is presented in accordance with research questions.

Contextual Characteristics of the Setting

Data for this study was collected at 20 breast screening events over eleven months. Forty percent of the screenings were held at health care facilities (private medical offices, clinics, community health centers); 40% were held at community events (health fairs, county fairs, community gatherings); and 20% at churches and community centers. Community settings varied from air conditioned schools to open spaces of church parking lots. Screening took place at mobile mammogram screening events in both urban (60%) and rural (40%) settings and was dependent upon the schedule of the sponsors.

Program data were also gathered in order to describe the contextual characteristics of the screening program and the larger setting in which women received follow-up care. An administrator of each agency involved in the mobile mammogram events completed the Agency Survey (Appendix F).
Agencies reported on two major areas of program services and staff. Services included the agency geographic service range, the distance a woman may travel for follow-up care if the mammogram was abnormal, availability of public transportation, and program offerings for breast cancer screening and follow-up. The geographic service range of the agencies varied between 25 and 100 (mean 45) miles. The range a woman traveled for follow-up care varied from 25-100 (mean 65) miles. Public transportation was readily available in urban areas, while rural areas relied primarily on medical taxis, requiring advance reservation. Program offerings for breast cancer screening and follow-up was reported to be similar in all sites as far as outreach, educational activities, and written educational materials available for women in both English and Spanish. Some programs reported offering exams by a nurse practitioner or physician before the mammogram was performed (66.7%) and others did not (33.3%). Women who saw a provider before the mammogram received one to one attention and a clinical breast exam as part of the screening. Urban programs reported sites for follow-up care were numerous and chosen based upon a woman’s residential location. Rural programs reported sites for follow-up were limited, often with only one imaging site for a large geographic area.

Agencies also reported on staff characteristics to include gender, ethnicity, languages spoken, staff mix of case managers and other personnel, as well as case management structure. The agencies reported staff to be primarily female (mean 73.4%) and bilingual in English and Spanish (mean 37%). Staff composition varied, with 66% of programs reporting having at least one promotora, or lay health educator, and 33% reported also having at least one patient navigator. The number of case managers remained constant with two case managers per program, while the number of women screened in the individual programs varied (range 86-
2030, mean 699, sd 916.56) in the past calendar year. Case management structure was reported as shared or not shared with 43% of agencies reporting a shared mode of case management. Shared case management means that in addition to the primary agency, staff from outside agencies made contact with women needing follow-up. Outside staff worked in facilities involved in the follow-up care for provider visits, diagnostics and treatment after an abnormal mammogram. Slightly more than half of the agencies (57%) reported no shared case management, meaning one case manager maintained individual contact with women through the entire follow-up phase.

A small percentage (5.5%) of women screened had no formal case management. These women were screened at events without Well Woman Health Check as a co-sponsor. At these events, the mobile mammography agency assumed case management functions for the women with abnormal results. These functions included telephone contact of participants and referrals for follow-up care. The amount of direct agency contact with women in these cases was limited to notification only. No dedicated case manager position existed within the mobile mammography unit agencies.

In summary, three contextual characteristics of the program services and staff varied among the agencies providing mammography screening and follow up services. The three contextual characteristics included providing services in a rural versus urban location, providing clinical breast exams at the time of mammogram screening or not, and whether or not case management was shared with outside agencies.
Sample

Most of the women present for mammograms approached the table set up for the study, expressed interest in the survey and took a flier. The majority (58.0%) of women who received the mammogram screening agreed to participate in the study. The number of women screened at each event varied as did the number of surveys gathered (range 12-71, mean 34).

The survey was distributed to 394 participants and 380 surveys were returned and scored. Surveys were excluded (n = 14) if women declined after consent (n = 6); had greater than 10% missing data (n = 5); or left with the survey (n = 3). The mean age of the larger group of participants (n= 349) was 50.1 years and ranged from 33- 83 years (Table 3). Women completed the survey in either English (50.5%) or Spanish (49.5%). The majority of participants resided in urban (63%) and self identified as being Hispanic (58.7%).

Demographics for women with abnormal mammograms

Demographic characteristics for the subgroup of women (n = 31) with abnormal mammograms BIRAD categories 0, 3, 4, 5, are depicted in Table 3. The mean age was 51.1 years and ranged from 40- 62 years. The majority completed the survey in the Spanish (61.3%). The majority of participants resided in urban (87%) areas and self identified as Hispanic (64.5%).
**TABLE 3: Statistics: General Demographics of Participants**

<table>
<thead>
<tr>
<th></th>
<th>Mammogram Results BIRAD 1, 2</th>
<th>Mammogram Results BIRAD 0, 3, 4, 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>349</td>
<td>31</td>
</tr>
<tr>
<td>Valid</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>50.1</td>
<td>51.1</td>
</tr>
<tr>
<td>Language of Survey (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>50.5</td>
<td>38.7</td>
</tr>
<tr>
<td>Spanish</td>
<td>49.5</td>
<td>61.3</td>
</tr>
<tr>
<td>Location: Urban (%)</td>
<td>63.0</td>
<td>87.0</td>
</tr>
<tr>
<td>Ethnicity (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>58.7</td>
<td>64.5</td>
</tr>
<tr>
<td>Caucasian</td>
<td>33.6</td>
<td>25.8</td>
</tr>
<tr>
<td>Native American / Alaskan</td>
<td>3.5</td>
<td>0</td>
</tr>
<tr>
<td>African American</td>
<td>2.9</td>
<td>6.5</td>
</tr>
<tr>
<td>Asian / Other</td>
<td>1.3</td>
<td>3.2</td>
</tr>
</tbody>
</table>

**Reliability and Validity of the Instruments**

**Exploratory Data Analysis**

Initial analysis involved exploratory data analysis (EDA). EDA provided an overview of data quality and potential issues that required decisions early before statistical analysis of the relationships within the model were attempted. Descriptive statistics and tests for normality and homogeneity of variance were utilized. A determination was made not to correct distribution of results. Kendall’s Tau correlation coefficient was used due to non-normalcy of the outcome variable: time to first follow-up appointment for recommended health care in women with abnormal mammograms. Cases with more than 10% of data missing were omitted from analysis (n=5).

**Reliability**

Reliability of the instruments was tested by examination of the subscales in the SHSHN and HADS. Cronbach’s alpha (α) reliability coefficients of .80 or greater was expected for well
developed subscales of the instruments. Some aspects of the survey contained newer items specific to breast cancer screening and outcomes, in which case alpha .70 or greater was sought.

Reliability results of the three satisfaction subscales of the Survey of Health Status and Health Needs (SHSHN) included Specific Event Satisfaction: Last Health Visit (alpha .955); General Health Care Satisfaction: Mammograms (alpha .950); and General Health Care Satisfaction: Health Visits (alpha .974). Since internal consistency was not expected for any other portion of the SHSHN survey, no other reliability estimates were conducted. Reliability of the Hospital Anxiety and Depression Survey was also examined using Cronbach’s alpha: Anxiety (alpha .789) and Depression (alpha .713).

Validity

Tests of construct validity included factor analysis of the three satisfaction scales in the SHSHN, Value of Health Care in the SHSHN, and Anxiety and Depression scales in the HADS. Factor analysis tested the internal structure of the three subscales and the extent to which the variable components measured what they intended to measure. Kaiser- Meyer- Olkin Measure of Sampling Adequacy (KMO) statistic greater than .5 was expected (range 0- 1). Results in the .5-.7 range were considered mediocre, results between .7-.8 were good, .8-.9 considered great, while results greater than .9 were considered superb (Field, 2005). Bartlett’s Test of Sphericity was expected to be significant at less than .05. Initial Eigenvalues of greater than one were expected, although some sources advise to retain factors greater than .7 (Field, 2005).

Construct validity was measured for the SHSHN and HADS with Factor Analysis utilizing Varimax rotation method with Kaiser normalization. Kaiser- Meyer– Olkin (KMO) measure of sampling adequacy (SHSHN > .9; HADS > .8) and significance of Bartlett’s Test of
Sphericity (.000) was acceptable for all subscales tested. All Eigenvalues were greater than 1.0.

For the SHSHN, the three satisfaction subscales and Value of Health Care were measured. Components of Specific Event Satisfaction: Last Visit loaded on one factor and explained 66.6% of the variance. Components of General Health Care Satisfaction: Mammograms loaded on one factor and explained 69.9% of the variance. Components of General Health Care Satisfaction: Visits loaded on one factor and explained 81.3% of the variance. Components of Value of Health Care loaded on three factors, and explained 62.5% of the variance. Construct validity of the HADS included the anxiety scale and the depression scale. Components of the anxiety scale loaded on one factor and explained 48.9% of the variance. Components of the depression scale loaded on one factor and explained 41.7% of the variance.

**Results of Women with Normal Mammograms**

The results of the larger group of women surveyed are presented in Appendix G. Frequencies, means, and standard deviations for predisposing and enabling factors, perceived needs and satisfaction characteristics are included. Results of women with normal mammograms are not included in this text as this group is not the basis of analysis and for purposes of parsimony.

**Results of Women with Abnormal Mammograms**

**Outcomes**

The amount of time it took participants to appear for the first follow up visit after an abnormal mammogram is measured as the variable: Time from Results Notification to First Follow-up Appointment (Table 4). This was the dependent variable in this study and is the mean sum of the number of days from the time a letter of notification of results was sent from the
mammography facility and the number of days a call was made from the case manager to the
date the woman appeared for the first follow-up appointment (Median 15.0 days, sd 38.340).
The skewness divided by the standard error of skewness value was > +/- 1.96 (2.78). Time from
Results Notification to First Follow-up Appointment met assumptions of independence and
homogeneity of variance, but because this variable was not normally distributed, Kendall’s
correlation coefficients were reported.

**TABLE 4: Statistics: Outcomes**

<table>
<thead>
<tr>
<th>Mean Time from Results Notification to First Follow-up Appointment:</th>
</tr>
</thead>
<tbody>
<tr>
<td>n Valid</td>
</tr>
<tr>
<td>Missing</td>
</tr>
<tr>
<td>Median</td>
</tr>
<tr>
<td>Std. Deviation</td>
</tr>
<tr>
<td>Minimum (days)</td>
</tr>
<tr>
<td>Maximum (days)</td>
</tr>
<tr>
<td>Early Responders: Follow-up &lt; or = to 14 days of results notification (%)</td>
</tr>
<tr>
<td>Late Responders: Follow-up &gt; or = to 15 days of results notification (%)</td>
</tr>
<tr>
<td>Follow-up within 60 days of notification: (%)</td>
</tr>
<tr>
<td>Follow-up 60-90 days from notification: (%)</td>
</tr>
<tr>
<td>No follow-up 90 days from notification: (%)</td>
</tr>
</tbody>
</table>

The percentage of women who had incomplete or abnormal results and required follow-up for additional health care was 8.2% of participants. The Time from Results Notification to First Follow-up Appointment ranged from 1 to 110 days, with 45% of participants following up within 14 days of notification and 55% of participants more than 14 days. Most participants (77.4%) returned for a follow-up appointment within 60 days; 6.5% followed up between 60 and 90 days; and 16.1% of participants did not follow-up at all by 90 days.
Results of Women with Abnormal Mammograms Related to Research Questions

The first aim of this study was to describe the contextual characteristics of the agencies and locations served by the mobile mammography units and the relationships with use of health services in women with abnormal mammograms. The first research question is below.

1. What are the relationships between contextual characteristics and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

Contextual Characteristics

Three contextual characteristics were examined in the subset of women with abnormal mammograms to include Geographic Location, Clinical Breast Exam at the time of screening mammogram, and Shared Case Management with outside agencies. Geographic Location was a dichotomous variable categorized as rural or urban. Clinical Breast Exam, a dichotomous variable, was coded as: breast exam conducted at time of screening yes/ no. Shared Case Management, another dichotomous variable, was coded as case management shared with outside agencies yes or no.

All three contextual variables were analyzed with correlations to measure the linear relationship between contextual variables and the Mean Time from Results Notification to First Follow-up Appointment (Table 5).
TABLE 5: Statistics: Contextual Characteristics

<table>
<thead>
<tr>
<th>Mammogram Results</th>
<th>Correlation One-tailed, n = 31†</th>
</tr>
</thead>
<tbody>
<tr>
<td>BIRAD 0, 3, 4, 5</td>
<td>τ</td>
</tr>
<tr>
<td>n = 31†</td>
<td>p</td>
</tr>
<tr>
<td>Geographic Location:</td>
<td></td>
</tr>
<tr>
<td>Urban (%) (coded 2)</td>
<td>83.9</td>
</tr>
<tr>
<td>Breast Exam (%)</td>
<td></td>
</tr>
<tr>
<td>No (coded 0)</td>
<td>87.1</td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>12.9</td>
</tr>
<tr>
<td>Shared Case Management (%)</td>
<td></td>
</tr>
<tr>
<td>No (coded 0)</td>
<td>6.5</td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>93.5</td>
</tr>
<tr>
<td>τ</td>
<td>.273</td>
</tr>
<tr>
<td>p</td>
<td>.038*</td>
</tr>
<tr>
<td>τ</td>
<td>-.295</td>
</tr>
<tr>
<td>p</td>
<td>.027*</td>
</tr>
<tr>
<td>τ</td>
<td>.223</td>
</tr>
<tr>
<td>p</td>
<td>.073**</td>
</tr>
</tbody>
</table>

Dep Variable: Mean Number of Days from Notification to First Follow-up Appt
† unless otherwise noted
*significant < .05, one tailed; **significant <.10, one tailed

Living in an urban geographic location (τ .273, p < .05, one-tailed) was associated with more time to follow-up, having a clinical breast exam (τ -.295, p < .05, one-tailed) was associated with less time to follow-up and having shared case management (τ .223, p < .1, one-tailed) was associated with more time to the first follow-up appointment for recommended health care after abnormal mammography.

The second aim of this study was to describe individual characteristics and the relationships with use of health services in women with abnormal mammograms. The next three research questions are listed below.

2. What are the relationships between predisposing characteristics and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?
3. What are the relationships between enabling characteristics and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

4. What are the relationships between characteristics pertaining to perceived needs and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

**Predisposing Characteristics**

The predisposing individual characteristics examined in this study included demographic, social and belief characteristics. Predisposing demographic characteristics were Age, Family History of Cancer, having a previous Abnormal Mammogram, and having a previous personal History of Cancer (Table 6). The majority (76.7%) of women had no first degree relative with a history of female cancer and most (89.7%) had no previously abnormal mammogram. None of the women had previous breast cancer and only a small percentage (3.2%) had any cancer and this was skin cancer.

Correlations between predisposing demographic individual characteristics and the dependent variable, Mean Number of Days from Notification to First Follow-up Appointment were analyzed (Table 6). No significant correlations were found with predisposing demographic characteristics and the dependent variable.
TABLE 6: Statistics: Predisposing Characteristics: Demographic

<table>
<thead>
<tr>
<th>Mammogram Results</th>
<th>Correlation</th>
<th>( \tau )</th>
<th>( P )</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BIRAD 0, 3, 4, 5</strong></td>
<td>n = 31†</td>
<td>( \tau )</td>
<td>( P )</td>
</tr>
<tr>
<td>Age in years</td>
<td>Mean</td>
<td>51.1</td>
<td>.089</td>
</tr>
<tr>
<td></td>
<td>Std Dev</td>
<td>6.675</td>
<td></td>
</tr>
<tr>
<td>Family History of CA (%)</td>
<td>n = 30</td>
<td>-0.081</td>
<td>.303</td>
</tr>
<tr>
<td>No (coded 0)</td>
<td>76.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>23.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abnormal Mammogram (%)</td>
<td></td>
<td>.194</td>
<td>.111</td>
</tr>
<tr>
<td>No (coded 0)</td>
<td>89.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>10.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>History of CA (%)</td>
<td></td>
<td>.095</td>
<td>.269</td>
</tr>
<tr>
<td>No (coded 0)</td>
<td>96.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>3.2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Dep Variable: Mean Number of Days from Notification to First Follow-up Appt
† unless otherwise noted

The predisposing social characteristics in this study included Education, Literacy, Work Status, Marital Status and Perceived Support (Table 7). Education was operationalized as the number of years in school. Mean year of education was 9.39 (sd 4.014) and ranged from 0-16 years. Literacy was measured as the ability to read the news and 83.9% of participants reported they could read the local newspaper. Work Status was measured as currently employed or not employed, with the majority (71.0%) of the sample reporting being unemployed Most of the participants reported being married (71%). Perceived Support was operationalized as internal or external support. Most women identified an external support system (71%) and included family, friends, clergy, health providers or others; while less of the group identified their support system as internal, and included self or God (29%).

Correlations between the predisposing social characteristics and the dependent variable Mean Number of Days from Notification to First Follow-up Appointment were analyzed (Table
7). No significant correlations between social characteristics and the dependent variable were found.

**TABLE 7: Statistics: Predisposing Characteristics: Social**

<table>
<thead>
<tr>
<th>Mammogram Results</th>
<th>Correlation One-tailed</th>
<th>n = 31†</th>
</tr>
</thead>
<tbody>
<tr>
<td>BIRAD 0, 3, 4, 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n = 31†</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years in school (range 0-16)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>9.39</td>
<td>.014</td>
</tr>
<tr>
<td>Std Dev</td>
<td>4.014</td>
<td>.459</td>
</tr>
<tr>
<td><strong>Literacy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Read the News (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No (coded 0)</td>
<td>16.1</td>
<td>.037</td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>83.9</td>
<td>.404</td>
</tr>
<tr>
<td><strong>Work Status</strong></td>
<td></td>
<td>.027</td>
</tr>
<tr>
<td>Employed (%)</td>
<td>71.0</td>
<td>.431</td>
</tr>
<tr>
<td>No (coded 0)</td>
<td>29.0</td>
<td></td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>29.0</td>
<td>.347</td>
</tr>
<tr>
<td><strong>Married (%)</strong></td>
<td>29.0</td>
<td></td>
</tr>
<tr>
<td>No (coded 0)</td>
<td>71.0</td>
<td>.121</td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>71.0</td>
<td>.261</td>
</tr>
<tr>
<td><strong>Perceived Support (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal (coded 0)</td>
<td>29.0</td>
<td></td>
</tr>
<tr>
<td>External (coded 1)</td>
<td>71.0</td>
<td></td>
</tr>
</tbody>
</table>

Dep Variable: Mean Number of Days from Notification to First Follow-up Appt
† unless otherwise noted

The predisposing beliefs examined in the study included Value of Health Care, Attitudes toward Health Care, Fears Related to Health, Fears Related to Tests, and Fears Related to Health Care Costs (Table 8). Value of Health Care Services was created using factor analysis. These variables were the perceptions of conditions that require prompt health services and consisted of 27 items which were summed, then analyzed. Rotation converged on five iterations and loaded on three factors (all > .4), identified as Emergent Health Care Services, Non emergent Health Care Services and Women’s Health Care Services. Emergent Health Care Services ranged from
0-14 (mean 9.0, sd 5.66); Non emergent Health Care Services ranged from 0-8 (mean 3.35, sd 2.95); and Women’s Health Care Services range from 0-5 (mean 3.32, sd 1.94). The higher the score on each of the three variables, the more value of health care.

**TABLE 8: Statistics: Predisposing Characteristics: Beliefs**

<table>
<thead>
<tr>
<th>Mammogram Results</th>
<th>Correlation</th>
<th>One tailed</th>
</tr>
</thead>
<tbody>
<tr>
<td>BIRAD 0, 3, 4, 5</td>
<td>n = 31†</td>
<td>( \tau )</td>
</tr>
<tr>
<td><strong>Value of Health Care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergent</td>
<td>range 0-14</td>
<td>.204</td>
</tr>
<tr>
<td>mean, sd</td>
<td>9.0, 5.66</td>
<td></td>
</tr>
<tr>
<td>Non Emergent</td>
<td>range 0-8</td>
<td>.179</td>
</tr>
<tr>
<td>mean, sd</td>
<td>3.35, 2.95</td>
<td></td>
</tr>
<tr>
<td>Women’s</td>
<td>range 0-5</td>
<td>.098</td>
</tr>
<tr>
<td>mean, sd</td>
<td>3.32, 1.94</td>
<td></td>
</tr>
<tr>
<td><strong>Attitudes† (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use of Professional Health Care</td>
<td>n = 29</td>
<td>.030</td>
</tr>
<tr>
<td>No (coded 0)</td>
<td>31.0</td>
<td></td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>69.0</td>
<td></td>
</tr>
<tr>
<td><strong>Fears† (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health†</td>
<td>n = 29</td>
<td>.137</td>
</tr>
<tr>
<td>No (coded 0)</td>
<td>62.1</td>
<td></td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>37.9</td>
<td></td>
</tr>
<tr>
<td>Tests†</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No (coded 0)</td>
<td>83.9</td>
<td>.194</td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>16.1</td>
<td></td>
</tr>
<tr>
<td>Costs†</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No (coded 0)</td>
<td>9.7</td>
<td>.159</td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>90.3</td>
<td></td>
</tr>
</tbody>
</table>

Dep Variable: Mean Number of Days from Notification to First Follow-up Appt
† unless otherwise noted.
* significant < .01, one tailed

The majority (69%) of women reported in the Attitudes Toward Health Care the belief professional health care services should be sought only when family and friends cannot provide
the help needed. Fears comprised variables of worries or Fears about Health, Fears about Tests or procedures; and Fears about Costs, or how to pay for health care. Most women reported no Fears about Health (62.1%) or Fears about Tests or procedures (83.9%). In contrast, the majority of women reported they did have Fear about Costs (90.3%).

Correlations between belief characteristics and the dependent variable, Mean Number of Days from Notification to First Follow-up Appointment were analyzed (Table 8). Both Value of Health Care: Emergent Health Care ($\tau = .204, p < .1$, one-tailed) and Non Emergent Health Care ($\tau = .179, p < .1$, one-tailed) were significantly associated with more time to first follow-up appointment for recommended health care for women with abnormal mammograms. No significant relationship was found between Value of Health Care: Women’s Health Care, Attitudes toward Health Care, Fears Related to Health, Fears Related to Tests, and Fears Related to Health Care Costs with the dependent variable.

Enabling Characteristics

The enabling individual characteristics of finance and access to care were examined using descriptive statistics. Finance characteristics included Household Financial Status, Insurance Status, Out of Pocket Costs and the Perception of Financial Assistance for health care expenses (Table 9). Access to care included the characteristic of Transportation. Most participants reported Household Financial problems with “not having enough money to pay bills” (29.0%), or “barely making ends meet” (54.8%). Fewer women reported “enough money to pay bills with a little extra” (16.1%) and none reported “enough money to do whatever we want.” The majority of participants were uninsured (93.5%) and almost half reported no monthly out of pocket health care costs (48.4%) citing lack of medical visits. Participants who did report out of pocket costs
visits, co-pays, medicine, lab, imaging, or medical devices) reported less than $50.00 per month (25.8%), $50- $100 per month (9.7%), $101- $200 (12.9%), and $201- $300 per month (3.2%).

Most of the women responded “no” or “unsure” when asked if they thought they had the ability to get financial help to pay for the medical care one might need if have breast cancer (71%).


<table>
<thead>
<tr>
<th>Mammogram Results BIRAD</th>
<th>Correlation n = 31</th>
</tr>
</thead>
<tbody>
<tr>
<td>0, 3, 4, 5 n = 31†</td>
<td>τ</td>
</tr>
<tr>
<td>Finance</td>
<td></td>
</tr>
<tr>
<td>Household Status† (%)</td>
<td></td>
</tr>
<tr>
<td>Not enough for bills (coded 1)</td>
<td>29.0</td>
</tr>
<tr>
<td>Barely makes ends meet (coded 2)</td>
<td>54.8</td>
</tr>
<tr>
<td>Enough to pay bills (coded 3)</td>
<td>16.1</td>
</tr>
<tr>
<td>Enough to do what we want (coded 4)</td>
<td>0.0</td>
</tr>
<tr>
<td>Insurance Status† (percent)</td>
<td></td>
</tr>
<tr>
<td>No (coded 0)</td>
<td>93.5</td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>6.5</td>
</tr>
<tr>
<td>Out of Pocket Costs† (percent)</td>
<td></td>
</tr>
<tr>
<td>None (coded 0)</td>
<td>48.4</td>
</tr>
<tr>
<td>&lt;50 (coded 1)</td>
<td>25.8</td>
</tr>
<tr>
<td>51-100 (coded 2)</td>
<td>9.7</td>
</tr>
<tr>
<td>101-200 (coded 3)</td>
<td>12.9</td>
</tr>
<tr>
<td>201-300 (coded 4)</td>
<td>3.2</td>
</tr>
<tr>
<td>&gt;300 (coded 5)</td>
<td>0.0</td>
</tr>
<tr>
<td>Perception of Financial Assistance† (percent)</td>
<td></td>
</tr>
<tr>
<td>No, unsure (coded 0)</td>
<td>71.0</td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>29.0</td>
</tr>
</tbody>
</table>

Dep Variable: Mean Number of Days from Notification to First Follow-up Appt
† unless otherwise noted
*significant < .05 one tailed; **significant <.10, one tailed

Correlations between enabling finance characteristics and the dependent variable, Mean Number of Days from Notification to First Follow-up Appointment were analyzed (Table 9).

Having out of pocket costs (τ -.218, p < 0.1, one-tailed) and perceptions of financial assistance (τ -.271, p < .05, one-tailed) were both significantly associated with less time to the first follow-up appointment for recommended health care for women with abnormal mammograms.
Variables of Household Financial Status and Insurance Status were not significantly associated with the dependent variable.

Participants responded on their opinions related to ease of obtaining transportation for health care with the group fairly evenly divided (Table 10). The majority of women reported transportation was “difficult” (35.5%) or “very difficult” (9.7%); while an almost equal number of women reported “no problem” (32.3%), “easy” (16.1%), or “very easy” (6.5%).

**TABLE 10:** Statistics: Enabling Characteristics: Access

<table>
<thead>
<tr>
<th>Mammogram Results BIRAD</th>
<th>Correlation n = 31†</th>
</tr>
</thead>
<tbody>
<tr>
<td>0, 3, 4, 5</td>
<td>τ</td>
</tr>
<tr>
<td>n = 31†</td>
<td>p</td>
</tr>
<tr>
<td><strong>Access</strong></td>
<td></td>
</tr>
<tr>
<td>Transportation for healthcare† (%)</td>
<td>.027</td>
</tr>
<tr>
<td>No problem (coded 0)</td>
<td>32.3</td>
</tr>
<tr>
<td>Very easy (coded 1)</td>
<td>6.5</td>
</tr>
<tr>
<td>Easy (coded 2)</td>
<td>16.1</td>
</tr>
<tr>
<td>Somewhat difficult (coded 3)</td>
<td>35.5</td>
</tr>
<tr>
<td>Very difficult (coded 4)</td>
<td>9.7</td>
</tr>
</tbody>
</table>

Dep Variable: Mean Number of Days from Notification to First Follow-up Appt
† unless otherwise noted

There was no significant correlation between the enabling characteristic of Transportation for health care and the dependent variable, Mean Number of Days from Notification to First Follow-up Appointment.

**Perceived Need Characteristics**

The individual characteristics pertaining to perceived needs examined in this study fell into two categories: Status and Patterns. Status included Current Breast Symptoms, Anxiety, Depression, and overall Health Status. Patterns included Past Follow-up Pattern and Preventive Pattern (Table 11). The majority of participants had no current breast symptoms (77.4%). Scores
for anxiety revealed most of the participants were in the normal range (67.7%) or with mild
(25.8%) anxiety. Most participants (74.2%) also had scores in the normal range on the
depression instrument and less than one fourth (22.6%) had mild symptoms of depression. None
of the participants scored in the severe range for anxiety or depression. Participants reported their
overall Health Status ranging from “extremely” healthy to “not at all” with “extremely” (3.2%),
“very” (29%), “moderately” (41.9%), “somewhat” healthy (19.4%); and “not at all” (6.5%).

Past Follow-up Pattern, a dichotomous variable was an indicator of participants’
responses to past follow-up recommendations by health providers. Women either had follow-up
or did not have follow-up according to recommendations. Most of the women (67.7%) reported
having no recommendations for care from a provider because they did not have health care visits.
Of those who did have health care visits and received recommendations for follow-up care,
16.1% reported following up as recommended and 16.2% did not.

Preventive Pattern, the percentage of screening tests participants had in the past year,
ranged from 0-1.0. A score of 0 meant no screening tests were done and 1.0 indicated all the
tests that would be expected of participants in this age range receiving recommended levels of
health care were completed in the past year (mean .354, sd .225). Only 3.2% of participants
reported having all appropriate screening tests in the past year.
### TABLE 11: Statistics: Perceived Needs: Status and Patterns

<table>
<thead>
<tr>
<th>Mammogram Results</th>
<th>Correlation One-tailed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>BIRAD</td>
</tr>
<tr>
<td>0, 3, 4, 5</td>
<td></td>
</tr>
<tr>
<td>n = 31†</td>
<td></td>
</tr>
</tbody>
</table>

**Status**

<table>
<thead>
<tr>
<th>Breast Symptoms (%)</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No (coded 0)</td>
<td>77.4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (coded 1)</td>
<td>22.6</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Anxiety (%)**

| 0-7 normal (coded 0) | 67.7             |        |    |       |
| 8-10 mild (coded 1)  | 25.8             |        |    |       |
| 11-15 moderate (coded 2) | 6.5            |        |    |       |
| 16 or > severe (coded 3) | 0.0          |        |    |       |

**Depression (%)**

| 0-7 normal (coded 0) | 74.2             |        |    |       |
| 8-10 mild (coded 1)  | 22.6             |        |    |       |
| 11-15 moderate (coded 2) | 3.2            |        |    |       |
| 16 or > severe (coded 3) | 0.0          |        |    |       |

**Health Status (%)**

| Extremely good (coded 1) | 3.2             |        |    |       |
| Very good (coded 2)      | 29.0             |        |    |       |
| Moderately good (coded 3) | 41.9          |        |    |       |
| Somewhat good (coded 4)  | 19.4             |        |    |       |
| Not at all (coded 5)     | 6.5              |        |    |       |

**Patterns (%)**

**Past Follow-up Pattern**

| No recommendations/ no visits | 67.7             |        |    |       |
| Recommendations made, no follow-up (coded 0) | 16.1         |        |    |       |
| Recommendations made, had follow-up (coded 1) | 16.1        |        |    |       |

**Preventive Pattern (mean, sd)**

| Range 0-1 (coded 0: no screening tests to 1: all screening tests in the past year) | .355, .225 |        |    |       |

Dep Variable: Mean Number of Days from Notification to First Follow-up Appointment. † unless otherwise noted.

*significant < .001, two tailed; **significant < .05 one tailed

Variables related to perceived needs were analyzed using correlation with the dependent variable, Mean Number of Days from Notification to First Follow-up Appointment (Table 11).
Having breast Symptoms ($\tau$.313, $p < .05$, one-tailed) was associated with less time to first follow-up appointment for recommended health care for women with abnormal mammograms.

Variables of Anxiety, Depression, overall Health Status, Past Follow-up Pattern, and Preventive Pattern were not significantly associated with the dependent variable.

The third aim of this study was to describe satisfaction with health care and the relationships with use of health services in women with abnormal mammograms. Research questions 5-7 are listed below.

5. What is the relationship between satisfaction with the most recent specific event of health care and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

6. What are the relationships between satisfaction with previous health care service in general and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

7. To what extent did women follow recommendations for care within 14 days of notification of an abnormal mammogram?

**Satisfaction with Health Care**

Results of previous health care satisfaction with the most recent health care visit and satisfaction with mammograms and health care visits in general are found in Table 12. The variable Specific Event Satisfaction: Last Health Visit is a mean satisfaction sum referring to the participant’s last visit with a health care provider. Participants scored on 14 general items, which were rated on a 5 point Likert scale ranging from 1: “very happy” to 5: “very unhappy” (median 1.500, sd .733).
General Health Care Satisfaction: Mammograms and General Health Care Satisfaction: Health Visits were also satisfaction scores referring to how participants rated general health services received for mammograms and testing and health visits. The variables were mean sums on 11 general items rated on a 5 point Likert scale that ranged from 1: “very happy” to 5: “very unhappy.” Results of both General Health Care Satisfaction: Mammograms (median 1.000, sd .782) and General Health Care Satisfaction: Health Visits (median 1.000, sd 1.187) indicated fairly high satisfaction.

**TABLE 12:** Statistics: Satisfaction

<table>
<thead>
<tr>
<th>Mammogram Results</th>
<th>Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>BIRAD 0, 3, 4, 5</td>
<td>n = 31†</td>
</tr>
<tr>
<td>n = 31†</td>
<td>τ</td>
</tr>
</tbody>
</table>

**Specific** (range 1-5)
Event: Last Health Visit (median, sd) (coded 1 “very happy” to 5 “very unhappy”)

1.500, .733
.190
.073**

**General** (range 1-5)
Health Care: Mammograms (median, sd) (coded 1 “very happy” to 5 “very unhappy”)

1.000, .782
.328
.008*

Health Care: Visits (median, sd) (coded 1 “very happy” to 5 “very unhappy”)

1.000, 1.187
.007
.479

Dep Variable: Mean Number of Days from Notification to First Follow- up Appt. † unless otherwise noted
*significant < .05, one tailed; **significant <.10, one tailed

Correlations between the three satisfaction variables and the outcome variable: Mean Number of Days from Notification to First Follow- up Appointment were analyzed (Table 12).

Specific Event Satisfaction: Last Health Visit (τ .190, p < 0.1, one- tailed) and General Health Care Satisfaction: Mammograms (τ .328, p <.05, one- tailed) were both significantly associated with more time to the first follow- up appointment when participants were less satisfied.
General Health Care Satisfaction: Visits was not significantly correlated with the outcome variable.

**Outcomes**

Research question seven addressed to what extent women followed recommendations for care within 14 days of notification of an abnormal mammogram. Results indicated 45% of participants did not follow-up for the first appointment within fourteen days of notification of results. The outcomes for the study were presented in more detail at the beginning of this chapter and can be found in Table 4.

In summary, analysis of correlations indicated several significant associations between independent variables and the outcome variable: Mean Number of Days from Notification to First Follow-up Appointment in the subset of women with abnormal mammograms. Examination of the variables in this study indicated significant associations with the outcome of use of health services as follow-up after health screening in several categories to include: contextual characteristics, predisposing, enabling and perceived needs as well as satisfaction (Figure 2).
Summary

Data for this study were collected at 20 mobile mammography breast screening events over an eleven month period. Program data were also gathered in order to describe the contextual characteristics of the screening program and the larger setting in which women received follow-up care. The survey was distributed to 394 participants and 380 surveys were returned and scored. Women with abnormal mammograms were followed by chart review for up to 90 days.
Reliability and validity was measured for both survey instruments, the SHSHN and HADS, and found to be satisfactory.

Analysis of the subset of women with abnormal mammograms in this study involved correlations to look at the relationships between the independent variables and the outcome variable: Mean Time from Results Notification to First Follow-up Appointment. Eleven variables were significantly correlated with the outcome variable to include: Geographic Location, Clinical Breast Exam, Shared Case Management, Value of Health Care: Emergent, Value of Health Care Non emergent, Out of Pocket Costs, Perception of Financial Assistance, Breast Symptoms, Specific Event Satisfaction: Last Health Visit, and General Health Care Satisfaction: Mammograms.

The percentage of women who needed follow-up due to incomplete or abnormal results was 8.2% of the participants. Time from Results Notification to First Follow-up Appointment ranged from 1 to 110 days, with 45% of participants following up within 14 days of notification and 55% of participants more than 14 days. The percent of women with abnormal mammograms who had no follow-up as recommended by 90 days were 16.1%.
CHAPTER 5: DISCUSSION

Introduction

This chapter discusses the research findings associated with indicators that facilitate use of health services for diagnosis and treatment after health screening. The findings associated with analysis of a subset of women with abnormal mammography are discussed related to the research questions, limitations, prior research and recommendations for future research.

Discussion Related to Research Questions

The purpose of this study was to describe contextual characteristics of the health care setting and individual characteristics of women who participated in health screening, and relationships with the outcome of use of health services. The indicators that impede or facilitate follow-up on recommendations for health care after a medical issue has been identified are complex. The overarching question of this study is whether or not there were significant relationships between the contextual characteristics and the individual characteristics of women with abnormal mammography and follow-up on recommendations for health care after health screening. This study examined contextual characteristics of the settings and four areas of individual characteristics including: predisposing and enabling factors, perceived needs, and satisfaction and their associations with use of health services. The need to better identify patients at risk for loss to follow-up after health screening is clearly important to improve patient outcomes in a financially restricted health environment. This study explored seven research questions with a subset of women screened for breast cancer with mobile mammography and found to have abnormal results. The following discussion will present the outcome variable,
address these seven questions, and present analysis, limitations, prior research and future research recommendations.

**Outcome Variable**

The percentage of women who had incomplete or abnormal results requiring additional follow-up care was 8.2% in this study. This is less than the percentage in the literature which identifies approximately 10-15% of women undergoing mammography require further diagnostic tests (Wujcik & Fair, 2008) and much less than a recent large retrospective study conducted in Tennessee which indicated 37% of women screened required follow-up care.

The amount of time it took participants to appear for the first follow-up visit after an abnormal mammogram is measured as the variable: Time from Results Notification to First Follow-up Appointment. This variable was the dependent variable in this study and is the mean sum of the number of days from the time a letter of notification of results was sent from the mammography facility and the number of days a call was made from the case manager to the date the woman appeared for the first follow-up appointment. The time for participants in this study ranged from 1 to 110 days. Most participants returned for a follow-up appointment within 60 days (77.4%); a smaller number (6.5%) followed up between 60 and 90 days; a number of participants (16.1%) did not have any follow-up by 90 days. The percentage of women with incomplete or abnormal findings without follow-up at 60 days is 22.6% in this study. These findings are slightly less than a retrospective study that found 30% of women experience delay of greater than 60 days (Wujcik et al., 2009). It is important to note evidence indicates delays of more than three months in women with symptomatic breast cancer are associated with increased rates of breast cancer recurrence and death (Wujik & Fair, 2008).
The amount of time from the screening mammogram date to notification of results for participants fits with other studies which ranged to as many as 133 days (Wujcik & Fair, 2008). The amount of variance in the time from notification of results for the participants between the mobile mammography agency and the case managers was unexpected, however. Recognition of these delays created the need to remove this variation from the variables so the amount of time to follow-up best reflected information about the participants and not the agencies. These circumstances resulted in development of a mean of these two time frames so results were as accurate as possible. It unknown if other studies reported in the literature actually made similar accommodations for the time lag associated with notification of results.

Reasons for lengthy delay in notifying participants of results of screening were not entirely clear. One explanation may be that the collaborative partnerships were relatively new and the internal procedures for communication were being developed (personal communication, 2009). Secondly, the community response to the outreach done by the collaborative partners was very favorable and resulted in a sudden influx of more participants into the agencies’ work flow than was anticipated or experienced in the past. This created disequilibrium within the agencies involved and required reorganization of procedures and manpower (personal communication, 2009). While these organizational issues were beyond the control of the research team; effect upon the study, the participants, and follow-up must be considered a limitation. Future research could better anticipate the effect internal agency changes might have on communication with participants. Further research into the contextual characteristics is warranted. Longitudinal study design with participant survey at specific data points to gather information on the effect of
agency interaction on follow-up may prove useful to better understand participant response to recommendations for follow-up after health screening.

**Research Question One**

1. What are the relationships between contextual characteristics and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

Research question one examined the contextual characteristics of the settings in which mobile mammography screening was delivered to participants and the organizational features that varied among the agencies sponsoring the screening events. These data largely served to describe the setting for mobile mammography screening. Three contextual characteristics were extracted due to variation between the agencies that sponsored mobile mammography screening and case managed follow-up services. The three contextual characteristics included Geographic Location: Urban versus Rural, Clinical Breast Exam at the time of screening mammogram, and Shared Case Management with outside agencies. Analysis of these variables included correlations with the dependent variable Mean Time from Results Notification to First Follow-up Appointment. Significant correlations were found with the outcome variable for all three contextual variables which are further described below.

Geographic location was significantly correlated with the outcome. Urban location had a positive relationship with the outcome and inversely, rural location was negatively associated. These findings suggest being an urban dweller is related to more days to follow-up after health screening, while being in a rural environment is associated with fewer days to follow-up.
These findings are of interest since they are in contrast to reports from sponsoring agencies. The difficulty rural participants have with limited public transportation, large distances to travel for health care and less availability of follow-up facilities were listed as problematic. However, difficulties with access to health care for both urban and rural living are multifaceted. A study of Tennessee women and use of mammography (n = 1922) compared screening utilization between rural and urban dwellers. The findings indicate that after controlling for factors such as less education, lower income, lack of health insurance, and others, rural residence was not associated with utilization of health services (Brown, Fitzhugh, Neutens & Klein, 2009). Since urban and rural location may be closely associated with other factors influencing use of health services future research would be recommended. Small sample size is clearly a limitation of this study. More research with larger samples to better discern covariates may evolve the knowledge of associations with urban or rural locations and use of health services after health screening.

The variable, Clinical Breast Exam, was negatively correlated with the outcome variable: Mean Time from Notification of Results to Follow-up. This suggests that having a clinical breast exam is related to fewer days between notification of abnormal results and receiving follow-up care. The provider exam involves not only physical examination, but also differences in the level of attention given to the participants during screening. When performing a clinical breast exam, the health care provider “lays on hands,” implying a more personal health care encounter than a simple mammography. In addition, the provider usually gives an opinion about findings in the exam. These factors may stimulate a more rapid response to recommendations for follow-up care for patients.
The results of this study are in alignment with others that support the importance of a personal relationship with a health provider and having an exam to improve screening, health care utilization, and outcomes (Battaglia et al., 2010; Sadler et al., 2010; Brown et al., 2009; Blewett et al., 2008; Blackman & Masi, 2006). Newly released guidelines indicate the clinical evidence is not sufficient to determine the added benefit or harm of clinical breast exam in overall improvement of cancer detection and outcomes (U.S. Preventive Services Task Force, 2009). As shifts in breast cancer screening recommendations are being made to make screening more evidenced based and cost effective, providers may want to consider if it is the actual clinical breast exam or the education and support provided with the clinical breast exam that is of most importance in improving health outcomes after screening.

An emerging trend was found for the variable Shared Case Management in a positive relationship with the outcome variable suggesting sharing case management responsibilities with outside agencies was related to more days to the first follow-up appointment. While an argument for shared case management to efficiently handle large caseloads of women being screened for breast cancer is reasonable, the consequences may lead to negative effects on timely follow-up. The question of whether dilution of personal contact and lack of continuity might occur when case management is shared with staff from outside agencies must be considered. Continuity and how to best provide it in a cost contained health care environment presents unique challenges. Studies of use of Promotoras and Patient Navigators to mitigate the tangle of health care complexities provide support for the importance of continuity (Palmieri et al., 2009; Ferrante, Chen & Kim, 2008; Battaglia et al., 2007). The impact of case management on follow-up after health screening is not entirely clear. Further research to explore case management, what
functions have a positive effect on shortening follow-up response after health screening, and what roles can be shared with others without detriment to outcomes would be helpful.

The data answers the question affirmatively that the three contextual characteristics tested in this study have significant relationships with time to the first follow-up appointment for recommended care after health screening. Women who live in rural areas, have had a clinical breast exam with the mammogram and participate in non shared case management have significantly fewer days from notification of an abnormal finding to a follow-up visit.

A limitation of this study also includes a disproportion of questions pertaining to context with those related to individual characteristics of participants themselves. In this study, only three contextual variables were extracted for analysis as compared to 32 individual characteristic variables. Clearly, this imbalance speaks to the need to further explore context and the association with follow-up. A systematic review of 22 studies pertinent to delays in follow-up after mammography found patient barriers were most extensively described in the research, while research studies specifically aimed at the provider and health system were lacking (Wujcik & Fair, 2008). Recommendations stemming from this study would include further exploration of the provider, case manager, and health system context to facilitate further research and development of targeted interventions to improve follow-up patterns after health screening.

Questions two, three and four addressed the predisposing, enabling and perceived need characteristics examined in this study. These questions tested the relationships between these individual characteristics and the outcome variable of time to first follow-up appointment for recommended health care.
Research Question Two

2. What are the relationships between predisposing characteristics and the time to first follow-up appointment for recommended health care for women with abnormal mammograms?

Predisposing characteristics included demographic, social and belief characteristics. The predisposing demographic characteristics were Age, Family History of Cancer, having a previous Abnormal Mammogram, and having a previous personal History of Cancer. No significant correlations between these demographic characteristics and the outcome variable were found. While age varied, most of the women with abnormal mammography in this study did not have a family history of cancer, previous abnormal mammogram, or previous history of cancer. Homogeneity of the sample may account for lack of significant findings for the predisposing demographic variables.

The predisposing social characteristics in this study included Education, Literacy, Work Status, Marital Status and Perceived Support. No significant correlation between the social characteristics and the outcome variable were found. Homogeneity of the sample may also account for lack of significant findings for the predisposing social variables.

The predisposing beliefs examined in the study included Value of Health Care, Attitudes toward Health Care, and Fears Related to Health, Tests, and Costs of health care. Value of Health Care services was a variable of perceptions of conditions that require prompt health services. Factor analysis of this variable produced three loadings labeled: Emergent Health Care Services, Non emergent Health Care Services, and Women’s Health Care Services. The higher the score on each of the three variables, the more value of health care. An emerging trend was
found in significant positive correlations between Emergent and Non emergent Health Care and the outcome variable, suggesting the higher the value placed on these aspects of health care, the more days to follow-up. The data suggests that two predisposing beliefs variables: Emergent Health Care Services and Non emergent Health Care Services have significant relationships with time to the first follow-up appointment for recommended health care after health screening.

The results of Value of Health Care are counterintuitive to expectations if one considers that greater value placed on health care would seem to result in fewer days to follow-up. The results indicate the opposite is so, and therefore, bears further scrutiny. Since most people would likely seek professional health care for emergent issues, those that would seek a professional for non emergent issues are considered to place more value on health care. While small sample size and relative homogeneity of the sample may account for these results, a stronger argument could be made that the participants in this study were primarily uninsured, did not receive health care on a regular basis, and these circumstances may have influenced opinions on what aspects of health care were important. If women thought all conditions required prompt service, discrimination of the importance of specific variables would be lost. Additionally, if women were accustomed to managing health issues without professional medical attention, they might under-report conditions that otherwise would have prompted medical attention if health care were more accessible.

Support for the latter of these two explanations can also be found in examination of data on the beliefs variable: Attitudes toward Health Care, which explored the opinions of participants related to use of professional health services versus calling upon neighbors or family to solve the problem. Most women (69%) reported a belief that professional health care services should be
sought only when family and friends could not provide the help needed. If women held the belief that others should provide health care before help from professional health providers was summoned, they might be more likely to under-report health needs. Since the majority of women in this study were uninsured, and did not have regular health care, homogeneity of the sample may be a factor for why this variable was not significantly associated with follow-up.

All collaborating agencies independently reported participant fear to be a prominent barrier to follow-up after mammography. This study explored fears related to health, tests and costs with most women reporting have some form of fear, fear of costs (90.3%) being a prominent concern. Homogeneity of the sample on this variable may account for lack of statistically significant relationships with the outcome variable. Further research with larger samples is needed to gain knowledge on the facets of fear, and if elements of fear influence follow-up on recommendations for health care after health screening. Costs and finance are further explored in research question three.

**Research Question Three**

3. What are the relationships between enabling characteristics and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

The enabling individual characteristics examined in this study include finance and access to care through transportation. Finance characteristics included Household Financial Status, Insurance Status, Out of Pocket Costs and the Perception of Ability to get Financial Assistance for health care expenses. Correlations with the outcome variable revealed an emerging trend of significance for the variable Out of Pocket Costs. Perception of Financial Assistance was
significantly correlated with the outcome variable. Other enabling finance variables were not significantly correlated with the outcome variable.

The data answers the question affirmatively that two enabling finance variables: Out of Pocket Costs and Perception of Financial Assistance are significantly correlated with the time to the first follow-up appointment for recommended health care after health screening. Out of Pocket Costs correlated in a negative relationship with Mean Time from Results Notification to First Follow-up Appointment. The negative relationship suggests the more out of pocket costs, the fewer days to the first follow-up appointment. It may be difficult to understand why uninsured participants (93.5%) with out of pocket costs (51.6%) would respond earlier to recommendations for more health care and perhaps incur more debt. Perhaps having some out of pocket costs is an indicator of using health services which may contribute to earlier follow-up. Small sample size was a limitation in this study. Further research on finance and the association of out of pocket costs with follow-up after health screening with larger samples would be important. Teasing out associations of out of pocket costs with past health visits and how follow-up is affected would be of interest.

Perception of Financial Assistance was positively correlated with the outcome variable, Mean Time from Results Notification to First Follow-up Appointment. These data suggest participants who thought there was financial help to pay for follow-up care, followed up more quickly than those who did not believe there was financial help available.

In a largely uninsured population, Perception of Financial Assistance may be an important indicator for follow-up. Breast cancer screening is currently the only preventive care in the United States health system that is associated with financial assistance for uninsured
persons who, otherwise, would not qualify for public assistance through Medicaid/ AHCCCS. In fact, a diagnosis of breast cancer through the state agency of NBCCEDP would qualify a participant for payment for breast cancer diagnosis, treatment and reconstruction if the participant was a citizen of the United States. Additionally, agencies have some funding available to help non citizens with the cost of follow- up care (personal communication, 2009). Interestingly, information related to finance is not usually shared with women until a cancer diagnosis is confirmed. The reasons for not sharing information related to potential assistance early include changes in funding, availability of funds from outside sources, and verification of citizenship status (personal communication, 2009). This is important as the results of this study suggest that having this information could positively impact the follow- up on recommendations for additional care.

Issues related to finance, use of screening services and follow- up are important in our current cost contained environment (Ahern & Shen, 2009). Having information related to options early seems a logical factor for better health outcomes, and may be an important factor in locus of control and decision making, two aspects of timely follow- up after cancer screening found in recent literature (Fair et al., 2010; Polacek, Ramos & Ferrer, 2007). Further research would be important to better understand the facets of perceptions of financial assistance and associations with follow- up care after health screening. Specifically, an interventional study could be useful to see if sharing information related to financial assistance early versus later has potential to improve follow- up care and health outcomes.

Transportation for Health Care was not significantly correlated with the outcome variable in this population of women with abnormal mammograms. Participants were fairly evenly split
on this variable where half indicated transportation was a problem and the other half indicated transportation was not a problem. While all rural agencies reported transportation was an issue believed to impact follow-up, these results do not support this theory as the majority of women who were late responders were urban dwellers. Small sample size may be a limitation to examination of transportation and associations with time to first follow-up appointment for recommended health care after health screening.

The next section discusses perceived needs and associations with follow-up after mammography. Perceived needs are examined as health status and health patterns.

**Research Question Four**

4. What are the relationships between characteristics pertaining to perceived needs and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

The individual characteristics relevant to perceived needs examined in this study included Breast Symptoms, Anxiety, Depression, Health Status, Past Follow-up Pattern, and Preventive Pattern. Breast Symptoms was significantly negatively correlated with the dependent variable, Mean Time from Results Notification to First Follow-up Appointment. This suggests that women who have symptoms of breast abnormalities are more likely to follow-up sooner on recommendations for additional care than are women without symptoms.

The data answers the question affirmatively that perceived need characteristics of Breast Symptoms is significantly correlated with the time to the first follow-up appointment for recommended health care after health screening. The findings suggest women with breast symptoms have fewer days to follow-up. This is in contrast to findings from a recent large (n =
A retrospective study conducted in Tennessee, in which women with self-reported breast symptoms were more likely to experience delay in follow-up after abnormal mammography (Wujcik et al., 2009). The large sample size and the predominantly African American sample may account for this difference in study results. African American women have been identified as having the greatest delays in diagnosis and treatment (Adams et al., 2009; Gorin et al., 2006; Chu et al., 2003). African American women accounted for only 6.5% of the subgroup with abnormal mammograms requiring additional health care in this study.

The percentage of screening tests participants completed in the past year comprised the variable Preventive Pattern. The analysis showed no significant correlation between this variable and the outcome of Mean Time from Results Notification to First Follow-up appointment. While Preventive Pattern may not actually be a strong indicator of use of health services after health screening, there are considerations. In this group of participants who are mostly uninsured and without health visits, it is important to note, that unlike the free mammograms offered by the mobile unit, almost all of the other health screening tests analyzed as part of the variable, Preventive Pattern, would require a fee. In addition, unlike the mammogram screening, most of the tests would require orders from a medical provider. Both costs of the tests and need for a medical provider in order to have other screening tests may have contributed to the low percentage of women (3.2%) who reported having all of the recommended screening tests in the past year. A lack of other screening tests may certainly be considered a limitation for examination of Preventive Pattern in this study. Further research is needed to better understand this variable and whether or not it is a significant indicator for follow-up care after health screening.
Past Follow-up Pattern is a perceived needs variable that was not significant for correlations in this study. Past Follow-up Pattern is an indicator of the past follow-up recommended by the participant’s health provider such as additional tests, medications, or lifestyle changes and the response to those recommendations. Women either had the follow-up or did not have the follow-up according to those specific recommendations. Most of the women reported having no recommendations for care from a provider (67.7%), therefore, did not have health care visits. Of those who did make visits and received recommendations, approximately half reported they followed up as recommended and half did not. The small sample size may have contributed to this finding and is a limitation. Further research with a larger sample size could possibly provide meaningful results for this variable.

The next two research questions addressed the last aspect of the individual characteristics examined in this study: satisfaction. Previous health care satisfaction with the most recent health care visit and satisfaction with mammograms and health care visits in general were both measured in this study of women with abnormal mammograms.

**Research Question Five**

5. Is there a relationship between satisfaction with the most recent specific event of health care and the time to the first follow-up appointment for recommended health care for women with abnormal mammograms?

The variable Specific Event Satisfaction: Last Health Visit is a mean satisfaction sum referring to the participant’s last visit with a health care provider. Participants scored on 14 general items rated on a 5 point Likert scale with range from 1: “very happy” to 5: “very unhappy.” Correlation between Specific Event Satisfaction: Last Health Visit and the outcome
variable, Mean Time from Results Notification to First Follow-up Appointment indicated an emerging trend. Specific Event Satisfaction: Last Health Visit was significantly and positively correlated with the dependent variable: Mean Time from Results Notification to First Follow-up Appointment. Since the higher the score, the less satisfaction, the relationship with this satisfaction variable and the dependent variable suggests a longer time to follow-up for participants who were less satisfied with the last health visit. The data answers the question affirmatively that Specific Event Satisfaction: Last Health Visit has a significant relationship with follow-up on recommendations for care after health screening. Further discussion of this variable follows.

While it is possible, Specific Event Satisfaction: Last Health Visit is an important variable associated with use of health services and follow-up for recommended care after health screening, it is also possible the value of this variable is inflated for two reasons. First, social desirability bias, the phenomenon of ranking satisfaction higher in order to be viewed favorably, would be considered a possible inflation factor. Participants returned their surveys directly to the PI and research assistant when finished. Future research might take social desirability bias into better consideration and structure return of the surveys differently to reduce this factor. Secondly, many participants used the narrative section of the survey to express appreciation for having a free mammography service. In this group of mostly uninsured women who have not been getting health care visits regularly, being able to participate in a screening service important to them without charge may also contribute to the reverse of social desirability bias. In other words, women may be less critical of health services in order to avoid appearing ungrateful. Inflation of the value of Specific Event Satisfaction: Last Health Visit as described above is a
study limitation. So too, would loss of specific value related to this satisfaction variable be considered a limitation of this study.

Future research may also include examination of satisfaction data gathered by other groups and examination of narrative information. In this study, a limitation was identified when other groups began to collect satisfaction surveys on participants approximately five months into the study. This process created some confusion for the women, may have contributed to lower survey response, and lower accuracy for survey data gathered. For example, women were introduced to the study prior to screening, but were surveyed by the mobile unit staff for their own purposes while in the van. When women emerged from the mobile unit van, they believed they had already completed the entire survey. This confusion likely contributed to women not wanting to complete a second survey. Additionally, if women thought they already answered questions related to satisfaction, they may have contributed less detail to those sections of the SHSHN. While this occurrence was unexpected and outside the control of the research team, design of future research may anticipate this possibility and the consent process might allow for collaborative sharing of satisfaction data gathered on the participants from all immediate sources. The narrative information provided by the women may also be incorporated into future research as these data could prove to be important contributions to better understanding aspects of satisfaction and association with positive health outcomes. In the following section, research question six further explores satisfaction in general.
Research Question Six

6. What is the relationship between satisfaction with previous health care services in
general and the time to the first follow-up appointment for recommended health care
for women with abnormal mammograms?

General Health Care Satisfaction: Mammograms and General Health Care Satisfaction:
Health Visits are both satisfaction scores referring to how participants felt about general health
services received for mammograms and testing and health visits. Similar to specific satisfaction,
these variables are mean sums on 11 general items rated on a 5 point Likert scale with range
from 1: “very happy” to 5: “very unhappy.” Results of general health care satisfaction indicated
fairly high satisfaction with past mammograms and health visits. Correlations between these
satisfaction variables and the outcome variable Mean Time from Results Notification to First
Follow-up Appointment indicated General Health Care Satisfaction: Mammograms correlated
significantly with the outcome variable. Since higher scores indicate less satisfaction, the results
suggest that women who were less satisfied were slower to follow-up on the next medical
appointment. The data answers the question affirmatively that General Health Care Satisfaction:
Mammograms has a significant relationship with time to the first follow-up appointment for
recommended health care after health screening. Further discussion, limitations and
recommendations related to this variable follow.

The same limitations in this study discussed in question five apply to General Health
Satisfaction: Mammograms for social desirability bias and reverse social desirability bias. Future
research with a secondary analysis of the survey to explore the narrative information provided by
the participants as discussed in question five could also shed important light on understanding
satisfaction with mammograms in general and associations with follow-up after this important health screening. The variable General Health Care Satisfaction: Visits was not significantly correlated with the dependent outcome variable. In this population of uninsured women without regular health visits, the sample may have been too homogenous on this variable.

**Research Question Seven**

7. To what extent did women follow recommendations for care within fourteen days of notification of an abnormal mammography?

Forty five percent of participants followed-up with first appointments for diagnostics or treatment within fourteen days of notification of an incomplete or abnormal mammogram in this study. This measure is useful in terms of a marker of follow-up care but has limitations for describing the complexity associated with the phenomenon of women who accept screening for breast cancer, but do not return for follow-up care. A limitation associated with this measure is obtaining comparison with other studies conducted with women who do not return for follow-up after abnormal mammograms. A review of early and more recent research makes clear that researchers are not consistent in measures of delay for follow-up after incomplete or abnormal mammography, have not yet successfully defined what acceptable time frames are for follow-up, or how to measure them (Wujcik & Fair, 2008). Suggestions for future research should include gaining consensus on measures of delay for follow-up after abnormal mammograms and utilizing them in design of research studies.

**Limitations of the Study**

Limitations of the study have been discussed in relation to research questions and included small sample size, homogeneity of the sample related to being highly uninsured and
without regular medical care, organizational disequilibrium, and use of satisfaction surveys by other agencies at a point in the study. The reason for the low ratio of abnormal mammograms for the number of participants screened is unclear, although women experiencing abnormalities, such as a palpable mass, for example, may have been reluctant to participate and share personal information through the survey. The number of variables in the study along with small sample size is also a limitation for use of other statistical analysis or to division of the sample into groups for comparison, both of which could add important information regarding follow-up after health screening.

**Conclusion**

This study involved primary data collection over an eleven month period in a population of women seeking health screening mammograms through free, mobile mammography units in urban and rural Arizona. The potential barriers to follow-up on recommendations for health care to attain diagnosis and treatment after screening are complex. In this study, the research questions explored if there were relationships between contextual, predisposing, enabling, perceived needs and satisfaction characteristics and follow-up for recommended care after health screening. Variables in all categories were significantly associated with follow-up with particular focus upon organizational characteristics of services and staff; and individual characteristics of beliefs, finance, perceived needs related to status and patterns, and satisfaction.

Nursing is concerned for population health and the ability to cope with illness. Nursing care is focused on healing, but just as much so, on facilitation of health, coping and illness management. Use of research on barriers to follow-up after health screening has potential to contribute to intervention development. This research is important to nursing because
identification and removal of barriers to timely follow-up after health problems are identified constitutes key elements to improvement of outcomes.

The population of women chosen for this study was deliberate as female breast cancer screening is currently only one of two health screenings with avenues for access to health care through Medicaid for poorer and uninsured Americans. The second that qualifies is cervical cancer screening as both are under the NBCCEDP. In the first ten years of organized breast cancer screening in the U.S., a woman could attain free screening but if she found out she had a mass or other abnormality, diagnosis and cancer treatment options were severely limited beyond payment out of pocket. In 2002, this policy changed with the NBCCEDP raising the financial guidelines to qualify economically disadvantaged, uninsured women for Medicaid insurance. This move was thought to improve a huge health system disparity that violated human ethics: screening without options for treatment. In spite of eight more years of NBCCEDP and state efforts to reduce financial barriers associated with breast cancer, problems persist. Delays in eligibility, lack of security of outside funding, large numbers of uninsured persons who do not qualify for public health insurance or the NBCCEDP, and forced decisions to choose between living with serious illness or assuming substantial financial burden, are stark realities that this particular health disparity still exists in the U.S. health care system.

Lack of return for follow-up services after abnormalities in health screening may constitute a loss of precious screening dollars, delayed treatment and poorer health outcomes. Delayed treatment may result in later entry into the health care system with advanced stage disease. The effect of more progressed disease may then be more extensive and expensive cancer
care once individuals reenter the health system, burdening societal resources. Late stage cancerous breast disease likely results in less favorable health outcomes or early death.

Health disparity related to screening without adequate options for access to health care is not limited to women with breast abnormalities. It is widespread in the U.S. due to more than 46 million uninsured and solutions associated with health reform only on the horizon. This health disparity is a paramount issue for disadvantaged Americans and constitutes a glaring complexity in a medical system in profound need of repair.
APPENDIX A: REVIEW OF THE LITERATURE
## Review of literature: Follow-up for diagnostics and treatment after abnormal mammography

<table>
<thead>
<tr>
<th>Citation</th>
<th>Population</th>
<th>Methodology</th>
<th>Definition of Timely Follow-up</th>
<th>Results</th>
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</thead>
<tbody>
<tr>
<td>Battaglia, et al. (2006)</td>
<td>n= 1332</td>
<td>Interview and medical record review.</td>
<td>Arrival at diagnostic evaluation 120 days from the date the original appt was scheduled.</td>
<td>78% had timely follow-up during the intervention compared to 64% pre intervention. In adjusted analysis, the intervention group had 39% greater odds of timely follow-up compared to the pre intervention group.</td>
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<td></td>
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<td>Bivariate and multivariate logistic regression analyses were conducted to compare pre and post test patient navigator intervention using the care management model.</td>
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<td>Fair, A.M., et al. (2010)</td>
<td>n= 76</td>
<td>Retrospective chart review to identify women with abnormal mammograms, then letter and telephone contact to offer participation in the study and conduct the survey. Logistic regression to examine why women follow-up after abnormal mammography or not. Constructs included perceived susceptibility, perceived benefits, perceived barriers, breast cancer and cancer risk knowledge, self efficacy, cancer fatalism, health and spiritual health locus of control.</td>
<td>Resolution within six months</td>
<td>Women with lower internal health locus of control scores were two times more likely than women with higher scores to have inadequate follow-up after abnormal mammogram.</td>
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<tr>
<td>Study</td>
<td>n</td>
<td>Methodology</td>
<td>Findings</td>
<td></td>
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<tr>
<td>Gwyn, K., et al. (2004).</td>
<td>831</td>
<td>Interview and medical record review to measure three intervals: physician consultation to biopsy-proven diagnosis; diagnosis to treatment initiation; and physician consult to treatment initiation. Logistic regression was used to determine the contributions of various factors (socioeconomic; family, cancer, mammogram history; BSE and smoking) to differences between African American and white women.</td>
<td>Diagnosis delay categories of &lt; 1 month, 1–2 months, and &gt; 2 months. Treatment delay was dichotomized into categories of &lt; 1 month and &gt; 1 month. Clinical delay was dichotomized into categories of &lt; 3 months and &gt;3 months. 22.4% of African American women and 14.3% of white women had clinical delays of three months. Compared with white women, African American women were more likely to experience delays in diagnosis and treatment even after controlling for factors related to access to care (method of detection and insurance status) and poverty.</td>
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<td>Kerner, J.F., et al. (2003).</td>
<td>184</td>
<td>Interviews in home, clinic and community sites and medical record review. Logistic regression analyses were used to assess the association between patient and health care system factors and diagnostic resolution within three months of abnormal findings.</td>
<td>Index mammogram to diagnosis &lt;30 days. Within 3 months, 39% of women were without diagnostic resolution and 28% within 6 months. Neither socioeconomic status nor system barriers were associated with timely diagnostic resolution. Timely resolution was associated with mammogram severity, patients asking questions, or receiving next step information at the initial mammogram. Women with prior breast abnormalities were less likely to complete timely diagnostic resolution as were women with higher levels of cancer anxiety.</td>
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<td>Palmieri, F.M. (2009)</td>
<td>339</td>
<td>Descriptive statistical design using a nurse navigator for uninsured women.</td>
<td>Diagnosis within 60 days of screening mammogram. Time from screening mammogram to diagnosis was 60 days or less for 81% of participants. No differences were found between racial groups. Rescheduling and socioeconomic barriers were attributed to 19% who did not get timely diagnosis.</td>
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<tr>
<td>Study</td>
<td>Sample Size</td>
<td>Study Design/Methods</td>
<td>Follow-up Care</td>
<td>Findings</td>
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| Poon, E.G., et al. (2004)  | n= 126      | Prospective longitudinal study involving medical record review and patient survey.     | Follow-up mammogram, a surgical consult, or a breast biopsy within 7 months of the index abnormal screening mammogram. | 64% of the women with abnormal mammograms received appropriate follow-up care.  
After adjusting for age and insurance status, two factors were found to be associated with delivery of appropriate follow-up: 1) documentation of a follow-up plan in the medical record, and 2) patients’ understanding of the need for follow-up.  
No clinical or psychological characteristics were associated with follow-up care. |
| Rojas et al. (1996)       | n= 42 with abnormal mammogram results who agreed to be interviewed. | Survey using a structured telephone interview at three cancer screening clinics at an urban inner-city public hospital. | Non-compliance was defined as delayed follow-up (four to six months after the date of the mammogram), or no follow-up at the time of interview (more than 6 months after abnormal mammogram). | Women screened: 442. Women with abnormal mammograms: 62.  
Non-compliance rate was 50%.  
Among the 42 (68%) women who agreed to be interviewed, non-compliers were less likely to state that they had been told to receive follow-up than compliers.  
Non-compliant women were less likely to have suspicious mammography interpretations, and more likely to report barriers to follow-up: cost of lost wages and medical care, system barriers, or fears, than compliant women.  
There were no differences between the two groups for age, education, insurance, source of care, family history, knowledge or attitudes. |
APPENDIX B: PARTICIPANT SURVEY
Survey of Health Status and Health Needs

ID # ________________
Town ________________
Initial Contact Site and Location:
CHC________________
NBCCEDP______________
Surveyor Name ______________
Date of Survey _______________
Language of Interview:
Spanish ______________
English ______________
Both ______________

Survey used with permission of Dr. Joyce Verran, University of Arizona, College of Nursing (CMLNP Grant)
Part 1: Household Information

Instructions: Please fill in the blanks

1. Age (years) _______________________________________________________________

2. Number of years of school __________________________________________________

3. Level of education completed _____________________________________________

4. Are you able to read a local newspaper? Yes_______ No________

5. What is your ethnic background? ___________________________________________

6. Are you employed? _______ Number of hours per week? ______________________

7. What is your occupation? _________________________________________________

8. Are you working in this job? _____ If not, what is your job?____________________

9. Marital Status? __________________________________________________________

10. What language(s) are spoken at home?_______________________________________

11. What language(s) do you read?____________________________________________

12. Have you ever had an abnormal mammogram?_______________________________

13. Have you had cancer before? ______ Where? ___________ When? ___________

   What treatment did you receive? ___________________________________________

14. Have any blood relatives been diagnosed with breast cancer or cervical cancer? _________

   How are they related to you? ______________________________________________

15. Do you have any worries or fears about your health?_______ If so, please describe:

   ________________________________________________________________________
ID#__________

16. Do you have worries about the tests or procedures? _____ If so, please describe:
______________________________________________________________________________

17. Do you have worries or fears about how to pay for your health care? _____ If so, please
describe:________________________________________________________________________

Instructions: For the next questions, please check the best answer or fill in the blank.

18. Financially, your household:

_____ does not have enough money to pay bills.
_____ barely makes ends meet.
_____ has enough money to pay bills, with a little extra.
_____ has enough money to do whatever we want.

19. Do you have health insurance coverage? ________________________________________

If so, what type of insurance do you have? ________________________________________

20. What out-of-pocket expenses do you have for health care?
______________________________________________________________________________
______________________________________________________________________________

21. How much do you estimate you pay out-of-pocket monthly?

$__________ for insurance premiums
$__________ for co-pays
$__________ for medicine
$__________ for other. Please describe______________________________________________

22. Do you think you could get financial help to pay for the medical care you might need if
you have breast cancer? __________________________________________________________
______________________________________________________________________________

23. Who do you call upon with a problem you cannot solve by yourself? _______________
Part 2: Health Service Availability

Instructions: The next questions are about health service availability and reasons to use those services. You may check more than one answer for the questions.

1. In your opinion, the conditions that need prompt health care service are:

   _____severe bleeding
   _____burn
   _____breast lump
   _____change in the breast nipple
   _____change in the breast shape or skin
   _____breast pain
   _____chest pain
   _____painful sexual intercourse
   _____difficulty breathing
   _____bloody sputum (coughing up blood)
   _____ear pain
   _____back pain
   _____diarrhea
   _____flu
   _____cold
   _____childbirth
   _____broken bone
   _____pregnancy
   _____prolonged vomiting
   _____stomach pain
   _____severe dizziness
   _____severe headache/ migraine
   _____fever
   _____suicide threat
   _____family violence or abuse
   _____alcohol or drug overdose
   _____discharge from the vagina, penis or breast nipple
   _____other, please specify__________________________________________________
Instructions: For questions 2 and 3, please check the best answer.

2. In your opinion, getting transportation to obtain health care is:
   _____ very easy
   _____ easy
   _____ no problem
   _____ somewhat difficult
   _____ very difficult

3. In your opinion, professional health care is sought only when family and friends cannot provide the help needed: _____ yes _____ no

Part 3
A: Health Service Needs

1. How is your health? _____ Describe: ________________________________________________

2. Are you currently having any breast symptoms? _____ If so, please describe all your symptoms:

3. Do you have any worries or fears about your health? _____ If so, please describe:
Part 3:

B: Instructions: Please check **yes, no, unsure or not applicable (NA)** if you had the following screening tests **in the last year**:

<table>
<thead>
<tr>
<th>Screening test</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mammogram</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast exam by a medical provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colon/ rectal exam</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pap smear</td>
<td></td>
<td></td>
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<tr>
<td>Blood pressure check</td>
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<td></td>
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<td></td>
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<tr>
<td>Routine physical exam</td>
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<td></td>
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<td></td>
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<tr>
<td>Cholesterol</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eye exam</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urine check</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dental check up</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Vaccination/ Immunization</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Hearing exam</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (Describe)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (Describe)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Part 4: Health Care Acceptance

Instructions: The next questions are about your **last visit** with a health care provider. Please tell us about how you felt “**very happy**” to “**very unhappy**” about the visit by choosing the best number and writing it in the column to the right.

Very happy - 1; Somewhat happy - 2; Not sure/don’t know - 3; Somewhat unhappy - 4; Very unhappy - 5

<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The amount of time it took to get an appointment.</td>
<td>_____</td>
</tr>
<tr>
<td>2. The amount of time it took to get there.</td>
<td>_____</td>
</tr>
<tr>
<td>3. The amount of time you had to wait to see the health care provider.</td>
<td>_____</td>
</tr>
<tr>
<td>4. The amount of time the health care provider spent with you.</td>
<td>_____</td>
</tr>
<tr>
<td>5. The amount of time the health care provider listened to you.</td>
<td>_____</td>
</tr>
<tr>
<td>6. The amount of time the health provider listened to your complaints and fears.</td>
<td>_____</td>
</tr>
<tr>
<td>7. The amount of time given to listening to your opinion about your care.</td>
<td>_____</td>
</tr>
<tr>
<td>8. The amount of education or talk about what you could do about your health.</td>
<td>_____</td>
</tr>
<tr>
<td>9. The explanation given to you about your health concerns.</td>
<td>_____</td>
</tr>
<tr>
<td>10. The cost NOT paid by your insurance.</td>
<td>_____</td>
</tr>
<tr>
<td>11. The respect shown to you during the visit.</td>
<td>_____</td>
</tr>
<tr>
<td>12. The quality of the care provided.</td>
<td>_____</td>
</tr>
<tr>
<td>13. The ability of the provider or interpreter to communicate with you in your language.</td>
<td>_____</td>
</tr>
<tr>
<td>14. The visit to the health care provider, over all.</td>
<td>_____</td>
</tr>
<tr>
<td>15. Did your health care provider recommend any screening tests you did not have?</td>
<td>_____</td>
</tr>
</tbody>
</table>

If so, please explain:

______________________________________________________________________________

______________________________________________________________________________

16. Did your health care provider recommend any action due to results of the tests? _________

If so, please explain: ____________________________________________________________

______________________________________________________________________________

17. What did your provider ask you to do?_____________________________________

What did you do about the recommended action?____________________________________

18. Is your most recent or the mammogram you will have very soon a routine screening or because there is a problem?_________________________________________
Part 5 Outcomes:

Instructions: The next questions refer to how you feel about general health care services received. Please write the number that best reflects your feelings.

Very happy - 1; Somewhat happy - 2; Not sure/don’t know - 3; Somewhat unhappy - 4; Very unhappy - 5; NA- did not have the visit

<table>
<thead>
<tr>
<th></th>
<th>Mammogram &amp; Testing</th>
<th>Health Visit</th>
<th>Other</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Cost</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Quality</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Availability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Convenience</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Length of wait for your appointment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Helpfulness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Friendliness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Individual Attention</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Patience/ not feeling rushed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Genuine interest shown for you</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Cultural sensitivity</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please elaborate on any area above where you were not pleased with the visit or care given to you: ___________________________________________

________________________________________________________________________

________________________________________________________________________

1. How healthy would you say you are right now?
   ________ Extremely
   ________ Very
   ________ Moderately
   ________ Somewhat
   ________ Not at all

2. What do you mean by health? Please tell what extremely, moderately, etc. means to you:
   _____________________________________________________________________
   _____________________________________________________________________
   _____________________________________________________________________
3. What, if anything, would you change about the health care you are receiving now?
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

4. Is there anything else you care to tell us about the health care or services needed or available to you? _______________________________________________________________
______________________________________________________________________________

5. Would you be willing to be interviewed again in about a year? _____ Yes _____ No

Thank you very much for your participation and your time.

Please continue with the next evaluation.
The Hospital Anxiety and Depression Scale

Please place a check mark next to the best answer:

1. I feel tense or ‘wound up’:
   - Most of the time
   - A lot of the time
   - From time to time, occasionally
   - Not at all

2. I still enjoy the things I used to enjoy:
   - Definitely as much
   - Not quite as much
   - Only a little
   - Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:
   - Very definitely and quite badly
   - Yes, but not too badly
   - A little, but it doesn’t worry me
   - Not at all

4. I can laugh and see the funny side of things:
   - As much as I always could
   - Not quite so much now
   - Definitely not so much now
   - Not at all

5. Worrying thoughts go through my mind:
   - A great deal of the time
   - A lot of the time
   - From time to time, but not too often
   - Only occasionally

6. I feel cheerful:
   - Not at all
   - Not often
   - Sometimes
   - Most of the time

7. I can sit at ease and feel relaxed:
   - Definitely
   - Usually
   - Not often
   - Not at all

8. I feel as if I am slowed down:
   - Nearly all the time
   - Very often
   - Sometimes
   - Not at all
9. I get a sort of frightened feeling like ‘butterflies’ in the stomach:
   Not at all ☐ Occasionally ☐ Quite often ☐ Very often ☐

10. I have lost interest in my appearance:
    Definitely ☐ I don’t take as much care as I should ☐ I may not take quite as much care ☐ I take just as much care as ever ☐

11. I feel restless as if I have to be on the move:
    Very much indeed ☐ Quite a lot ☐ Not very much ☐ Not at all ☐

12. I look forward with enjoyment to things:
    As much as I ever did ☐ Rather less than I used to ☐ Definitely less than I used to ☐ Hardly at all ☐

13. I get sudden feelings of panic:
    Very often indeed ☐ Quite often ☐ Not very often ☐ Not at all ☐

14. I can enjoy a good book, radio or TV program:
    Often ☐ Sometimes ☐ Not often ☐ Very seldom ☐

Thank you. Please return your survey to the nurse researcher.
APPENDIX C: APPROVAL FROM HUMAN SUBJECTS PROTECTION
March 3, 2009

Ruth DeBoard, Doctoral Candidate
Advisor: Deborah Vincent, PhD
Department of Nursing
PO Box 210025

RE: PROJECT NO 08-1080-02 Breast Abnormalities: Identification of Indicators that Facilitate Use and Satisfaction with Health Service for Diagnosis and Treatment of Breast Cancer

Dear Ms. DeBoard:

We received your research proposal as cited above. The procedures to be followed in this study pose no more than minimal risk to participating subjects and have been reviewed by the Institutional Review Board (IRB) through an Expedited Review procedure as cited in the regulations issued by the U.S. Department of Health and Human Services [45 CFR Part 46.110(b)(1)] based on their inclusion under research categories 5 and 7. As this is not a treatment intervention study, the IRB has waived the statement of Alternative Treatments in the consent form as allowed by 45 CFR 46.116(d)(2).

Please make copies of the attached IRB stamped consent documents to consent your subjects. The need for documentation of informed consent has been waived for the agency survey, as the research involves no risks or procedures for which consent is normally required outside of the research context as stated in 45 CFR 46.117(c)(2).

Although full Committee review is not required, notification of the study is submitted to the Committee for their endorsement and/or comment, if any, after administrative approval is granted. This project is approved with an expiration date of March 2, 2010.

The Institutional Review Board (IRB) of the University of Arizona has a current Federal wide Assurance of compliance, FWA00004218, which is on file with the Department of Health and Human Services and covers this activity.

Approval is granted with the understanding that no further changes or additions will be made to the procedures followed without the knowledge and approval of the Human Subjects Committee (IRB) and your College or Departmental Review Committee. Any research related physical or psychological harm to any subject must also be reported to each committee.

A university policy requires that all signed subject consent forms be kept in a permanent file in an area designated for that purpose by the Department Head or comparable authority. This will assure their accessibility in the event that university officials require the information and the principal investigator is unavailable for some reason.

Sincerely yours,

Elaine G. Jones, PhD, RN, FNAP
Chair, Social and Behavioral Sciences Human Subjects Committee
EGJ/mm cc: Departmental/College Review Committee
APPENDIX D: INFORMED CONSENT
Subject Informed Consent
English Version

Study Title: Women’s use of health services for breast cancer screening

Introduction
You are being asked to take part in a research study. The information in this form is being given to you to help you decide if you do or do not want to enroll. The people doing this study will answer any questions you have and give you more information. If you decide to take part in the study, you will be asked to sign this consent form. A copy of this form will be given to you.

What is the purpose of this research study?
The reason for this study is to find out how women move through the health system while:

- having a mammogram and breast exam
- taking tests if the mammogram is not normal
- taking treatment for breast cancer
- getting support while treated for breast cancer

Why are you being asked to participate?
You are being asked to be in this study because:
1. You are age 18 or older
2. You have agreed to have a mammogram
3. You live in the state of Arizona

How many people will be asked to participate in this study?
About 400 women will be asked to be in this study. A smaller number of these women will have abnormal mammograms and need more health care.

What will happen during this study?
If you agree to be in this study, you will:
1. Fill out a survey form about your health status and health needs at the time of your mammogram.
2. The survey questions will be in Spanish or English, your choice.
3. A translator will be present to help you during the surveys.
4. If your mammogram is not normal, the nurse researcher will review your chart to learn about the health care and support given to you. The nurse researcher will review your chart approximately once a month for no more than 90 days.

How long will I be in this study?
Approximately 15 minutes of your time will be needed for the survey. Your chart will be reviewed only if your mammogram is not normal. In this case, your chart will be reviewed for no more than 90 days.
Are there any risks to me?
There is always the possibility of loss of confidentiality from your participation in the study, but we have measures in place to protect you. There is also the possibility you may feel uncomfortable answering some questions. If this happens, you may stop being in the study at any time or not answer any questions you do not wish to answer. There is no physical, financial or employment risk. Your current ability to get health care through Well Woman Health Check or other health care provider will not change by being a part of this study. Your current ability to get health care also would not change if you decided you did not want to be a part of this study.

Are there any benefits to me?
1. There are no direct benefits from being in this study.
2. Being in this research study may help doctors, nurses, and hospitals plan better care for other women being screened or treated for breast cancer.

Will there be any costs to me?
Other than your time, there are no costs to you to be in this study.

Will I be paid to participate in the study?
You will not be paid to participate in this study.

Will video or audio recordings be made of me during the study?
No recordings will be made of you during the study.

Will the information that is obtained from me be kept confidential?
The only people who will know that you were in this study will be the nurse doing the study and her assistants. Their names are: Ruth DeBoard, MS, RN, Doctoral Student; Sarah Granger, Student Nurse; Patricia Mazon- Brownell, Student Nurse; and Nidia Gastelum, Student Nurse.

1. The information you share will be confidential.
2. Your name will not be used in any reports or articles written about this study.
3. Individuals who have the job of protecting people who agree to be in research studies (Human Subjects Protection Program) and the teachers who are supervising the nurse doing the study may want to look at the information you share. If this happens, the information you share will be given to them but your name will not be included.

May I change my mind about being in this study?
Being in this study is your choice. You may decide to not be in the study. You may decide to stop being in the study at any time. Your current ability to get health care will not change if you decide not to be in the study.

Whom can I contact for more information?
You can get more information about the study. You can talk about any concerns you have. To do this, call the nurse doing the study Ruth DeBoard, MS, RN, Doctoral Student, or her assistants at 888-235-4164.
You may also call the University of Arizona Human Subjects Protection office at toll-free number 1-866-278-1455. You can call them if:

   1. You have questions about your rights of being in this study.
   2. Have questions or concerns.
   3. Have complaints about the study.
   4. Would like to give information about the study and cannot reach the nurse or her assistant.
   5. Want to talk to someone other than the nurse and her assistant.

You can also contact the Human Subjects Protection Program by email. Please use the following email address [http://www.irb.arizona.edu/contact/](http://www.irb.arizona.edu/contact/)

**Signature**

By signing this form, I confirm that:

   1. I have read (had explained to me) the information contained in the form.
   2. That the study has been explained to me.
   3. That my questions have been answered.
   4. I agree to be in this study.
   5. I do not give up any of my legal rights by signing this form.

__________________________________
Name (Printed)

__________________________________   ______________
Participant’s Signature      Date signed

**Statement by person obtaining consent**

I certify that I have explained the research study to the person who has agreed to participate, and that he or she has been informed of the purpose, the procedures, the possible risks and potential benefits associated with participation in this study. Any questions raised have been answered to the participant’s satisfaction.

__________________________________
Name of Study Personnel

__________________________________   ______________
Study Personnel Signature      Date signed
APPENDIX E: HIPAA WAIVER
Authorization Form for Use and Disclosure of Protected Health Information for Research

Study Title: Women’s use of health services for breast cancer screening

The United States government has issued a new privacy rule to protect the privacy rights of individuals enrolled in research. The Privacy Rule is designed to protect the confidentiality of an individual’s health information. This document hereafter known as an “Authorization for Use and Disclosure of Protected Health Information for Research” describes your rights and explains how your health information will be used and disclosed for this study.

PURPOSE

You are being invited to participate voluntarily in the above-titled research project. The purpose of this project is to help health providers better understand how women move through the health system when they receive health care. The women in this study are screening for breast cancer with mammogram and breast exam, may take more tests if their mammogram is not normal, or may need more health care if cancer is found. This study is being done so that health care providers may learn how women are supported while getting health care.

USE AND DISCLOSURE OF PROTECTED HEALTH INFORMATION

You will be asked for permission to allow the researchers to view your medical record. When a woman has a mammogram that returns with a problem, further tests are usually needed. This requires more health care. Your medical record would be reviewed only if the mammogram is abnormal.

Information in your health record that may be viewed includes:

1. Mammogram screening dates and results.
2. The follow up care recommended to you.
3. When and if you received that care.
4. When you were contacted by the agencies involved in your health care.
5. Other reports like ultrasound, biopsy and surgery reports.

This information will help health providers to understand the health care you received. Your medical information is stored by Well Woman Health Check or the community health center where you get health care. If you grant permission, Well Woman Health Check will supply your record to be viewed approximately once per month for no more than 90 days. If you have a problem and your mammogram is not normal, viewing your medical record will help researchers to learn about the care you receive. Your information will be confidential.
Your name will not be used in any reports or articles written about this study. Individuals who have the job of protecting people who agree to be in research studies (Human Subjects Protection Program) and the teachers supervising the nurse researcher doing the study may want to look at the information you share. If this happens, the information you share will be given to them, but your name will not be included. Your medical information will be linked to your name and kept until March 30, 2011. You have the right to access the information that may be created during this study as it relates to your treatment. Your access to this information will become available only after the study analyses are complete.

CONTACTS

You can obtain further information from the Principal Investigator, Ruth DeBoard, MS, RN, Doctoral Student, or her assistants at 888-235-4164. If you have questions concerning your rights as a research subject, you may call the Human Subjects Protection Program office at (520) 626-6721.

AUTHORIZATION

I hereby authorize the use or disclosure of my individually identifiable health information. I may withdraw this authorization at any time by notifying the Principal Investigator in writing. The address for the Principal Investigator is c/o Deborah Vincent, College of Nursing, P.O. Box 210203, Tucson, AZ 85721-0203. If I do withdraw my authorization, any information already given may not be withdrawn and may continue to be used. Once information about me is given, the researcher may use it as described above, and my information may no longer be protected by privacy regulations described above.

I may refuse to sign this authorization form. If I choose not to sign this form, I cannot participate in the research study. Refusing to sign will not affect my present or future medical care and will not cause any loss of benefits to which I am otherwise entitled. This authorization will expire on the date the research study ends. I will be given a copy of this signed authorization form.

__________________________
Participant’s Signature           Date

__________________________
Printed Name of Participant
APPENDIX F: AGENCY SURVEY
Agency Survey

The following questions pertain to the facility delivering health care services to women obtaining breast cancer screening, diagnostics or treatment. Your answers will be strictly confidential.

Name of primary facility: _________________________________________________________
Address: ______________________________________________________________________
County: ______________________________________________________________________

Please list the names of affiliated facilities with address and county:
________________________________________________________________________
________________________________________________________________________

The following questions pertain to the geographic service range of your facility:

1. What is the general service range or the distance patients travel to get to the primary facility listed above?
   a. Less than 25 miles
   b. 25-50 miles
   c. 51-100 miles
   d. Greater than 100 miles

2. What are the hours of operation for the primary facility above (circle all that apply):
   a. Less than 8 hours per day AND 5 days per week
   b. 8 hours per day AND 5 days per week
   c. More than 8 hours per day AND 5 days per week
   d. Weekend hours
   e. Evening hours

3. If a patient has an abnormal mammogram, what is the distance from your facility patients may have to travel to get further diagnostic care?
   a. less than 25 miles
   b. 25-50 miles
   c. 51-100 miles
   d. greater than 100 miles

4. If a patient has a diagnosis of breast cancer, what is the distance from your facility she may need to travel to get a visit with a surgeon?
   a. less than 25 miles
   b. 25-50 miles
   c. 51-100 miles
   d. greater than 100 miles
5. If a patient has a diagnosis of breast cancer, what is the distance from your facility she may need to travel to have surgery?
   a. less than 25 miles
   b. 25-50 miles
   c. 51-100 miles
   d. greater than 100 miles

6. Surgical options include:
   a. Free-standing surgical outpatient center
   b. Hospital

7. If a patient has a diagnosis of breast cancer, what is the distance from your facility she may need to travel to get radiation treatment?
   a. less than 25 miles
   b. 25-50 miles
   c. 51-100 miles
   d. greater than 100 miles

8. If a patient has a diagnosis of breast cancer, what is the distance from your facility she may need to travel to get a visit with an oncologist?
   a. less than 25 miles
   b. 25-50 miles
   c. 51-100 miles
   d. greater than 100 miles

9. If a patient has a diagnosis of breast cancer, what is the distance from your facility she may need to travel to get chemotherapy treatment?
   a. less than 25 miles
   b. 25-50 miles
   c. 51-100 miles
   d. greater than 100 miles

10. If a patient has had surgery for breast cancer, what is the distance from your facility she may need to travel to get a visit with a plastic surgeon for reconstruction care?
    a. less than 25 miles
    b. 25-50 miles
    c. 51-100 miles
    d. greater than 100 miles

11. If public transportation is available in your community, what is the furthest distance from your facility service is available?
    a. less than 25 miles
    b. 25-50 miles
    c. 51-100 miles
    d. greater than 100 miles
    e. no public transportation is available
The following questions pertain to the health needs of women screened for breast cancer through your facility in the past fiscal year:

12. What is the approximate number of women screened for breast cancer through your facility in the past fiscal year?
   a. less than 100
   b. 100-300
   c. 301-500
   d. more than 500

13. Of those women in question 12, what is the approximate number of women requiring further diagnostic care beyond screening mammogram?
   a. less than 100
   b. 100-300
   c. 301-500
   d. more than 500

14. Of those women in question 12, what is the approximate number of women with a diagnosis of breast cancer?
   a. less than 25
   b. 26-100
   c. 101-300
   d. more than 300

15. Of all of the women in question 12, what is the number of women who do not follow up for recommended care?

16. In your opinion, what would you say is the primary reason women do not follow up for recommended care after an abnormal mammogram?

17. In your opinion, what would you say would be appropriate interventions to improve women’s follow up after abnormal mammogram?

18. Please indicate which of the following services your facility offers to improve continuity of care for women undergoing screening, diagnostics or treatment for breast cancer (may circle more than one):
   a. Case Manager
   b. Patient navigator
   c. Lay health worker, Lay educator, Promotora
   d. Follow-up with the same primary care provider
   e. Other: ____________________________________________________________
19. Please indicate what outreach activities your facility participates in to bring breast cancer screening, diagnostics and treatment to women:
   a. Media campaign. Type(s):____________________________________________
   b. Mobile mammography services
   c. Organized activities to promote breast health awareness
      Describe____________________________________________________
   d. Other:______________________________________________________

20. Please choose the item that best describes the education your facility delivers to women about breast cancer screening, diagnosis and treatment (may circle more than one):
   a. Formal educational program delivered in a group setting
   b. Formal educational program delivered one on one
   c. Informal education delivered one on one
   d. Packet of written materials
   e. Packet of written materials in language(s) other than English.
      Languages:__________________________________________________
   f. Not sure who does the education
   g. No education offered at this time

The following questions pertain to the staff in the primary facility listed above:

21. What is the number of health care providers (Physicians, NPs, PAs) in your facility?
   a. none
   b. 1-3
   c. 4-6
   d. 7-10
   e. more than 10

22. What is the number of staff in your facility that work directly with women seeking care for breast cancer screening, diagnosis and treatment?
   a. none
   b. 1-3
   c. 4-6
   d. 7-10
   e. more than 10

23. Of the staff in question 19, how many are Case Managers?
   a. none
   b. 1-3
   c. 4-6
   d. 7-10
   e. more than 10
24. Of the staff in question 19, how many are Patient Navigators?
   a. none
   b. 1-3
   c. 4-6
   d. 7-10
   e. more than 10

25. Of the staff in question 19, how many are Lay Health Educators or Promotoras?
   a. none
   b. 1-3
   c. 4-6
   d. 7-10
   e. more than 10

26. What percentage of the health care providers (Physicians, NPs, PAs) in your facility are female?
   a. 0- 25%
   b. 26- 50%
   c. 51- 75%
   d. 76-100%

27. What percentage of the staff in your facility that work directly with women seeking care for breast cancer screening, diagnosis and treatment are female?
   a. 0- 25%
   b. 26- 50%
   c. 51- 75%
   d. 76- 100%

28. What percentage of the health care providers (Physicians, NPs, PAs) in your facility are non white?
   a. 0- 25%
   b. 26- 50%
   c. 51- 75%
   d. 76-100%

29. What percentage of the staff in your facility that work directly with women seeking care for breast cancer screening, diagnosis and treatment are non white?
   a. 0- 25%
   b. 26- 50%
   c. 51- 75%
   d. 76- 100%
30. What percentage of the health care providers (Physicians, NPs, PAs) in your facility speak a language other than English?
   a. 0-25%
   b. 26-50%
   c. 51-75%
   d. 76-100%

31. What percentage of the staff in your facility that work directly with women seeking care for breast cancer screening, diagnosis and treatment speak a language other than English?
   a. 0-25%
   b. 26-50%
   c. 51-75%
   d. 76-100%

32. If your facility employs a Case Manager, what percentage of time is spent on breast cancer screening, diagnosis or treatment related patient activities?
   a. 0-25%
   b. 26-50%
   c. 51-75%
   d. 76-100%

33. If your facility employs a Patient Navigator, what percentage of time is spent on breast cancer screening, diagnosis or treatment related patient activities?
   a. 0-25%
   b. 26-50%
   c. 51-75%
   d. 76-100%

34. If your facility employs a Lay Health Educator or Promotora, what percentage of time is spent on breast cancer screening, diagnosis or treatment related patient activities?
   a. 0-25%
   b. 26-50%
   c. 51-75%
   d. 76-100%

35. Is there anything else you would like to tell us about health care services provided for women seeking care for breast cancer screening, diagnosis and treatment?

___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

Thank you for your time.
APPENDIX G: RESULTS OF WOMEN WITH NORMAL MAMMOGRAMS
**Individual Characteristics: Predisposing** (n = 349 unless otherwise specified).

<table>
<thead>
<tr>
<th></th>
<th>Demo</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in years</strong></td>
<td>n = 348</td>
<td>Mean: 49.97, sd: 7.725</td>
</tr>
<tr>
<td><strong>Family History CA</strong></td>
<td>n = 338</td>
<td>No: 68.3%, Yes: 31.7%</td>
</tr>
<tr>
<td><strong>Abnormal Mammogram</strong></td>
<td>n = 343</td>
<td>No: 86.6%, Yes: 13.4%</td>
</tr>
<tr>
<td><strong>History of CA</strong></td>
<td>n = 347</td>
<td>No: 96.3%, Yes: 3.7%</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td><strong>Results</strong></td>
</tr>
<tr>
<td>Years school</td>
<td>n = 345</td>
<td>Mean: 11.28, sd: 3.880</td>
</tr>
<tr>
<td><strong>Literacy</strong></td>
<td></td>
<td><strong>Results</strong></td>
</tr>
<tr>
<td>Read News</td>
<td>n = 344</td>
<td>No: 3.5%, Yes: 96.5%</td>
</tr>
<tr>
<td><strong>Work Status</strong></td>
<td></td>
<td><strong>Results</strong></td>
</tr>
<tr>
<td>Employed</td>
<td>n = 344</td>
<td>No: 53.5%, Yes: 46.5%</td>
</tr>
<tr>
<td><strong>Married</strong></td>
<td>n = 337</td>
<td>No: 36.2%, Yes: 63.8%</td>
</tr>
<tr>
<td><strong>Perceived Support</strong></td>
<td>n = 345</td>
<td>Internal: 31.3%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>External: 68.7%</td>
</tr>
<tr>
<td><strong>Beliefs</strong></td>
<td></td>
<td><strong>Results</strong></td>
</tr>
<tr>
<td><strong>Value of Health Care</strong></td>
<td></td>
<td><strong>Results</strong></td>
</tr>
<tr>
<td>Emergent Health Care</td>
<td></td>
<td>Range: 0-14</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mean: 8.45, sd: 5.325</td>
</tr>
<tr>
<td>Non Emergent Health Care</td>
<td></td>
<td>Range: 0-8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mean: 2.48, sd: 2.631</td>
</tr>
<tr>
<td>Women’s Health Care</td>
<td></td>
<td>Range: 0-5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mean: 2.94, sd: 1.927</td>
</tr>
<tr>
<td><strong>Attitudes</strong></td>
<td></td>
<td><strong>Results</strong></td>
</tr>
<tr>
<td>Use of Professional Health Care</td>
<td>n = 342</td>
<td>No: 36.5%, Yes: 63.5%</td>
</tr>
<tr>
<td><strong>Fears</strong></td>
<td></td>
<td><strong>Results</strong></td>
</tr>
<tr>
<td>Health</td>
<td>n = 338</td>
<td>No: 64.2%, Yes: 35.8%</td>
</tr>
<tr>
<td>Tests</td>
<td>n = 340</td>
<td>No: 85.4%, Yes: 14.6%</td>
</tr>
<tr>
<td>Costs</td>
<td>n = 333</td>
<td>No: 19.0%, Yes: 81.0%</td>
</tr>
</tbody>
</table>
**Individual Characteristics: Enabling (n = 349 unless otherwise specified)**

<table>
<thead>
<tr>
<th>Finance</th>
<th>Results</th>
</tr>
</thead>
</table>
| Household | n = 346 | Not enough for bills: 21.1%  
| | | Barely makes ends meet: 54.6%  
| | | Enough to pay bills: 23.1%  
| | | Enough to do what we want: 1.2%  
| Insurance Status | No: 87.1%, Yes: 12.9% |
| Out of Pocket Costs | None: 51.6%  
| | <50: 16.3%  
| | 51-100: 8.6%  
| | 101-200: 11.2%  
| | 201-300: 8.6%  
| | >300: 3.7%  
| Perception of Financial Assistance | No, unsure: 87.6%  
| | Yes: 12.4% |

<table>
<thead>
<tr>
<th>Access</th>
<th>Results</th>
</tr>
</thead>
</table>
| Transportation for healthcare | n = 347 | No problem: 29.7%  
| | Very easy: 21.3%  
| | Easy: 23.1%  
| | Somewhat difficult: 20.2%  
| | Very difficult: 5.8% |
### Individual Characteristics: Perceived Needs (n = 349 unless otherwise specified)

<table>
<thead>
<tr>
<th>Status</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast Symptoms</td>
<td>n = 345</td>
</tr>
<tr>
<td></td>
<td>No: 81.4%, Yes: 18.6%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>n = 348</td>
</tr>
<tr>
<td></td>
<td>0-7 normal: 68.7%</td>
</tr>
<tr>
<td></td>
<td>8-10 mild: 19.0%</td>
</tr>
<tr>
<td></td>
<td>11-15 moderate: 11.2%</td>
</tr>
<tr>
<td></td>
<td>16 or &gt; severe: 1.1%</td>
</tr>
<tr>
<td>Depression</td>
<td>n = 348</td>
</tr>
<tr>
<td></td>
<td>0-7 normal: 80.5%</td>
</tr>
<tr>
<td></td>
<td>8-10 mild: 15.5%</td>
</tr>
<tr>
<td></td>
<td>11-15 moderate: 4.0%</td>
</tr>
<tr>
<td></td>
<td>16 or &gt; severe: 0.0%</td>
</tr>
<tr>
<td>Health Status</td>
<td>n = 345</td>
</tr>
<tr>
<td></td>
<td>Extremely healthy: 10.1%</td>
</tr>
<tr>
<td></td>
<td>Very healthy: 36.8%</td>
</tr>
<tr>
<td></td>
<td>Moderately healthy: 42.3%</td>
</tr>
<tr>
<td></td>
<td>Somewhat healthy: 9.0%</td>
</tr>
<tr>
<td></td>
<td>Not at All: 1.7%</td>
</tr>
<tr>
<td>Patterns</td>
<td></td>
</tr>
<tr>
<td>Past Follow-up</td>
<td>No recommendations/ no visits: 66.5%</td>
</tr>
<tr>
<td></td>
<td>Recommendations made/ no follow-up: 16.9%</td>
</tr>
<tr>
<td></td>
<td>Recommendations made/ had follow-up: 16.6%</td>
</tr>
<tr>
<td>Preventive</td>
<td>Mean: 306, sd: .238</td>
</tr>
</tbody>
</table>

### Individual Characteristics: Satisfaction (n = 349 unless otherwise specified)

<table>
<thead>
<tr>
<th>Specific</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Event: Last Health Visit</td>
<td>Median: 1.429, sd: .868</td>
</tr>
<tr>
<td>General</td>
<td></td>
</tr>
<tr>
<td>Health Care: Mammograms</td>
<td>Median: 1.000, sd: .635</td>
</tr>
<tr>
<td>Health Care: Visits</td>
<td>Median: 1.091, sd: 1.085</td>
</tr>
</tbody>
</table>
REFERENCES


