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A CHARACTERIZATION OF FAMILY HEALTH: IMPLICATIONS FOR BREAST CANCER SCREENING

By

Susan K. Hoppough

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ABSTRACT

A CHARACTERIZATION OF FAMILY HEALTH: IMPLICATIONS FOR BREAST CANCER SCREENING

By

Susan K. Hoppough

The goal of this qualitative research was to explore family ecosystem and life course factors associated with women's participation in breast cancer screening. This qualitative research involved 10 women, five self-described as White, and 5 self-described as African American, aged 40-55 years old. The intent of this research was to delve into how these women described factors associated with family ecosystem cultural values and beliefs in the context of life course influences on their decision to participate or not participate in breast cancer screening.

Concepts from family ecosystems Bubolz, Sontag, and the life course perspective by Price, McKenry & Murphy, provided the context for exploring factors associated with participation in screening. In this qualitative study, participants completed semi-structured interviews and completed ecomap descriptions of social, family, and work relationships.

Analysis of the data revealed five themes as factors contributing to the use of health care services and breast cancer screening. Learned health behaviors, knowledge dissemination, selective health messaging, access to services, and personal responsibility were consistently identified throughout the interview data.

While the theories presented formed the foundation for this research and helped to understand learned health behaviors and the use of screening services, the influence of communication within the family is limited. The use of a communication theory may have helped to understand the rationale behind the selective health messaging revealed in this study. Also, while the family ecosystem stresses the decision making processes used within the family in relation to values, needs, goals and standards, it does nothing to understand the barriers faced by women when they decide to use the services and the services are simply, not available. A focus on a communication theory and a social exchange theory would allow investigation in these unexamined areas.

DEDICATION

I dedicate this work to my family
To my husband, John
To my daughters Sarah and Anne
To their significant others, Chris and Mike
To my parents, Thomas and Anna Mae Dunlap
Your dedicated and persistent support
allowed me to accomplish this goal.

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This venture began with a dream. Without the support of family, friends, and mentors, this dream would not have become a reality. My years at Michigan State University have been filled with joy and I will leave with memories of friendships, learning, and a vision for the future.

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INTRODUCTION

The goal of this qualitative research was to explore family ecosystem and life course factors associated with women's participation in breast cancer screening. From an ecosystem perspective, the research was to also explore if there were values and beliefs expressed associated with the decision to participate in screening that may be indicative of culturally specific attributes of individualism and collectivism. The life course factors explored included both normative and non-normative events and transitions that influenced the decision-making process.

This qualitative research involved 10 women, five self-described as White, and 5 self-described as African American, who were aged 40-55. The intent of this research was to delve into how these women described factors associated with family ecosystem cultural values and beliefs in the context of life course influences on their decision to participate or not participate in breast cancer screening. The rationale for selecting this age range included the recommendation for annual mammography beginning at age 40 (ACS, 2003) and the many life course transitions and events experienced at this time by women individually and as family members. Each woman participated in one semi-structured interview designed to explore family ecosystem and life course factors associated with the decision to participate in screening. Women also completed an ecomap to describe the relationships within their life course. A review of the literature revealed a paucity of qualitative studies that have explored these factors among women who are educated, have higher levels of income and health insurance.

Background Information

This interest in breast cancer screening began with my mother's diagnosis of breast cancer. In particular, my mother is someone who, according to the literature, would most likely participate in screening on a regular basis and if diagnosed with breast cancer, the cancer would be in the early stages of the disease. That is, she is White, middle class, and a high school graduate. She had insurance coverage for her medical care, had a physician, and participated in regular screening. In addition, I am a nurse and could have provided her with additional information in her decision-making process. Yet, I was unaware that she was symptomatic of a breast lump for four years preceding her diagnosis. At the time of her first diagnosis, the breast cancer had metastasized to her axillary lymph notes, reducing her chances of long-term survival. She developed an ipsilateral recurrence of the breast cancer fiver years after the initial diagnosis. These led me to wonder what factors contributed to her decision-making related to screening and to the persons she included in the decision-making process. In my mothers' case, participants in the discussion included only her spouse and her physician.

After that experience, I participated in studies that focused on the caregiving of patients with cancer and cancer screening in primary care and Medicaid managed care organizations. As a doctoral student, I enrolled in courses that focused on underserved populations, including the elderly and ethnically diverse groups. There are common themes both experientially, within the literature and through anecdotal accounts about those who do not participate in screening. That is, racial/ethnic group membership, lack of education and lack of health insurance increase the likelihood of late stage diagnosis of cancer (Mikey, Vezina, Worden & Warner, 1997; Ayanian, Kohler, Abe & Epstein, 1993) as a result of non-participation or late participation. So, what was different about my mother and other women like her, and why was her experience more like that of women in certain racial/ethnic groups, and those with low income and less education? The ideas for this study arose from this background knowledge, from continuing scholarly pursuits in understanding breast cancer screening, and personal family experience with breast cancer.

Study significance

In 2003, an estimated 211,300 women with invasive breast cancer will be diagnosed and an estimated 39,800 are expected to die from the disease (ACS, 2003). In Michigan, 7,500 women will be diagnosed and an estimated 1,400 will die from breast cancer in 2003 (ACS, 2003). Also, an estimated 55,700 new cases of in situ breast cancer will be diagnosed with 85% specifically ductal carcinoma in situ. These breast cancers are those that are diagnosed as a result of screening with mammography (before invasive breast cancers are felt) (ACS, 2003).

Screening for breast cancer includes diagnostic tests recommended to all age-eligible women with the purpose of diagnosing early rather than late stage or invasive cancer. Between 1991 and 1995 early detection and improved treatment contributed toward a reduction in the U.S mortality rates (1.4%) related to breast cancer among younger women. The goal of early detection is to reduce mortality rates by discovering early stage cancer, when cure is more likely and treatment is less traumatic (Caplan, 1997; Kerlikowske, Grady, Rubin, Sandrock & Ernster 1995; Stowe & Schumann, 1999). Breast cancer continues to rank second in cancer deaths in women. As a result of both early detection and improved treatments, mortality rates after 1995 have declined by 3.2% with the largest decrease in White and African American younger women (ACS, 2003).

Women face a range of barriers to appropriate screening that includes lack of insurance, knowledge, and transportation. Programs such as the Breast Cancer and Cervical Cancer Program (Anonymous, 1993) have mitigated some of these access barriers by providing programs that offer mammography in mobile units to patients at low or no cost. The Breast and Cervical Cancer Mortality Act of 1990 focused on increasing screening for women with low income, limited access to insurance coverage, and minority group membership (Anonymous, 1993). In Michigan, in the second year of the program, locations for women to receive breast and cervical cancer screening increased by 260%, from 24 to 62 locations (Anonymous, 1993). Targeted programs and efforts to increase breast and cervical cancer screening among American Indian women include the training of nurses to deliver services though outreach programs (Petersen, Trapp, Vierkant, & Sellers, 2002). The American Cancer Society and other organizations offer educational seminars, workshops, and print media to increase knowledge related to cancer screening with the purpose of increasing the use of breast cancer screening services.

As stated by the 2000 Behavioral Risk Factor Surveillance System (BRFSS) in the Breast Cancer Facts & Figures (ACS, 2001a), the percentage of women in the United States over the age of 40 who had a recent mammogram was 62.6%. Even with efforts to increase access, those least likely to report having a recent mammogram were women with low income or less than a high school education and women from certain ethnic/racial groups (ACS, 2001a). We know little about the influence of life course events and family ecosystem factors associated with the use or non-use of breast cancer screening. In addition, we know little about how efforts to address these factors may increase screening.

To gain a better understanding of life course and family ecosystem influences, this study explored factors related to breast cancer screening and health among those women <u>most</u> likely to participate in screening—White women and African American women with *higher* levels of education and health insurance. It is known that low income and less education are descriptors of women who are less likely to participate in screening (ACS, 2001a). By selecting women who have higher levels of income and education it was felt that family ecosystem and life course factors associated with the decision to participate in screening services would be more evident in the targeted sample of White and African American women. Little is known about the factors that women consider when making the decision to participate in screening. This study explored the influence of health values and beliefs within a life course and a family ecosystem perspective on this decision-making process.

Theoretical Framework

Concepts from family ecosystems (Bubolz & Sontag, 1993) and the life course perspective (Price, McKenry & Murphy, 2000) provided the context for exploring factors associated with participation in screening.

Family ecosystems

The family ecosystem model involves three separate environments in which the environed unit (family) interacts with the human built/technological, social/cultural, and natural/physical environments. The social/cultural environment proposed by Bubolz and Sontag (1993) includes the relationship of other people to families (neighbors within communities), cultural constructions in the form of norms, cultural values and patterns of behavior, and social/economic institutions that influence behavior. Families interact and are interdependent with these influences. Social/cultural environmental factors of interest for this study include knowledge and beliefs about health that form the norms and patterns of behavior and how individuals view responsibility toward the health of those with less access to health care. Exploring these factors and whether they can be identified as culturally specific attributes of individualism versus collectivism are of interest in this study.

The social/cultural ecosystem considers family values, needs, the use of resources, and decision-making related to problem solving and achieving family goals (Bubolz & Sontag, 1993). Decision-making within the ecosystem model is an important consideration in whether or not women participate in screening. Decision-making functions to maintain the family's most important values and brings about non-disruptive change (Bristor, 1990).

Within a family, decision-making is based on an ideal state, and motivation is required in order to make a decision (Bristor, 1990). Problems arising within a family during decision-making occur when conflict exists between the self-interest of an individual and family well-being.

At other times, problems arise when a decision is based on conflicting values within the family system (Bristor, 1990). Components of a decision include values, goals, standards, and needs. Decision-making is a process requiring recognition of the need for a decision, weighing acceptable alternatives and facilitation of action toward the alternative. While people have different decision-making styles, all decisions reflect a process of ordering information for reflection and choice (Bristor, 1990).

Decision-making includes both rational and irrational components based on values, historical events influencing the decision, feelings, facts and observations of past decisions. Consequently, decision-making discriminates between useful and unimportant information and ends in an action that will achieve the objective. At times, individuals and families choose a course of action that is the least challenging and may not always be the best choice (Bristor, 1990). This model of decision-making may explain why uninsured or underinsured women chose to not participate in screening. The decision may be the result of weighing alternatives (paying out of pocket expenses for the test versus using resources to meet other family needs) and the conflict between self-interest and family well-being.

The family ecosystem model lends itself to exploring the decision-making process and social/cultural influences women experience through interactions with health care organizations that provide cancer-screening services. Despite efforts and supports for breast cancer screening, 20% of all age eligible women continue not to participate, and even fewer participate on a regular basis (ACS, 2001A).

Life course factors

A life course perspective provides the opportunity to view the individual within a family over the course of time with both a micro and macro system approach. The life course incorporates the effects of historical, generational, and individual time as influences on the way that individuals and families experience tasks and transitions (Bengston & Allen, 1993; Price et al., 2000). A life course view also allows for exploring the way that individuals interact with ecosystems in terms of their historical, generational, and individual times and how these perspectives affect transitions and events individuals may experience. Figure 1 schematically represents the ecosystem and life course frameworks related to participation in breast cancer screening. This figure represents the interrelationships between and among the family ecosystem environments superimposed along the life course perspective to demonstrate the varied factors influential in the decision to participate or not, in breast cancer screening (Figure 1).

Figure 2 represents conceptually, the factors influencing the decision to participate in breast cancer screening. The shaded area surrounds factors associated with the cultural context in which decision-making occurs. The cultural context includes knowledge, beliefs, and values related to breast health that influences the decision to participate in breast screening. The broken lines connected to income, education, and insurance represent those confounding factors eliminated in the sample selection process. Race is highlighted because only White and African American women will participate in the study, and the literature demonstrates there is a racial difference in screening for breast cancer (Wesley, Trapp, Vierkant & Sellers, 2002).

Figure 3 represents the decision-making process that includes recognition of the need, the value of health, the goal of participating in cancer screening and the standard used to measure the goal. This decision-making is an individual decision that occurs within the context of the family and may compete with the needs of the family.

Figure 1. Theoretical Framework Underlying Research

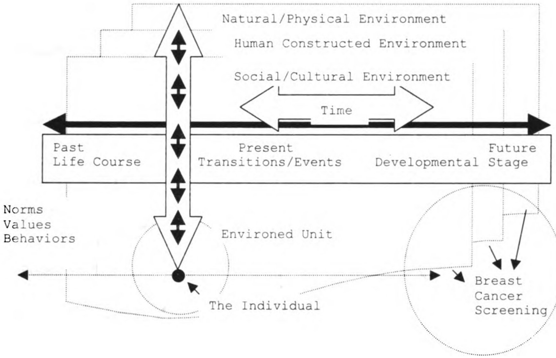


Figure 2. Conceptual Framework: Factors Influencing Decision Making.

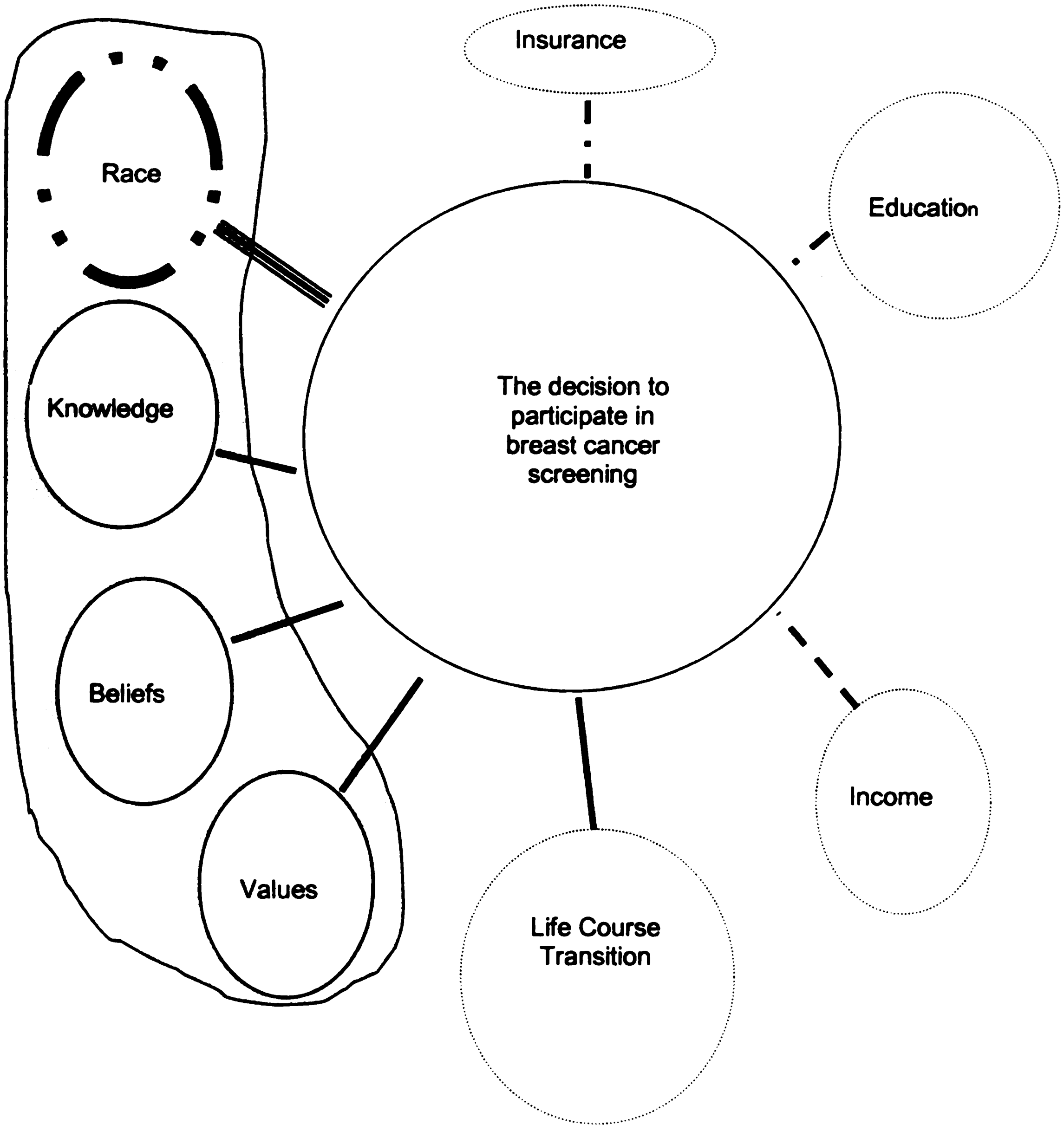
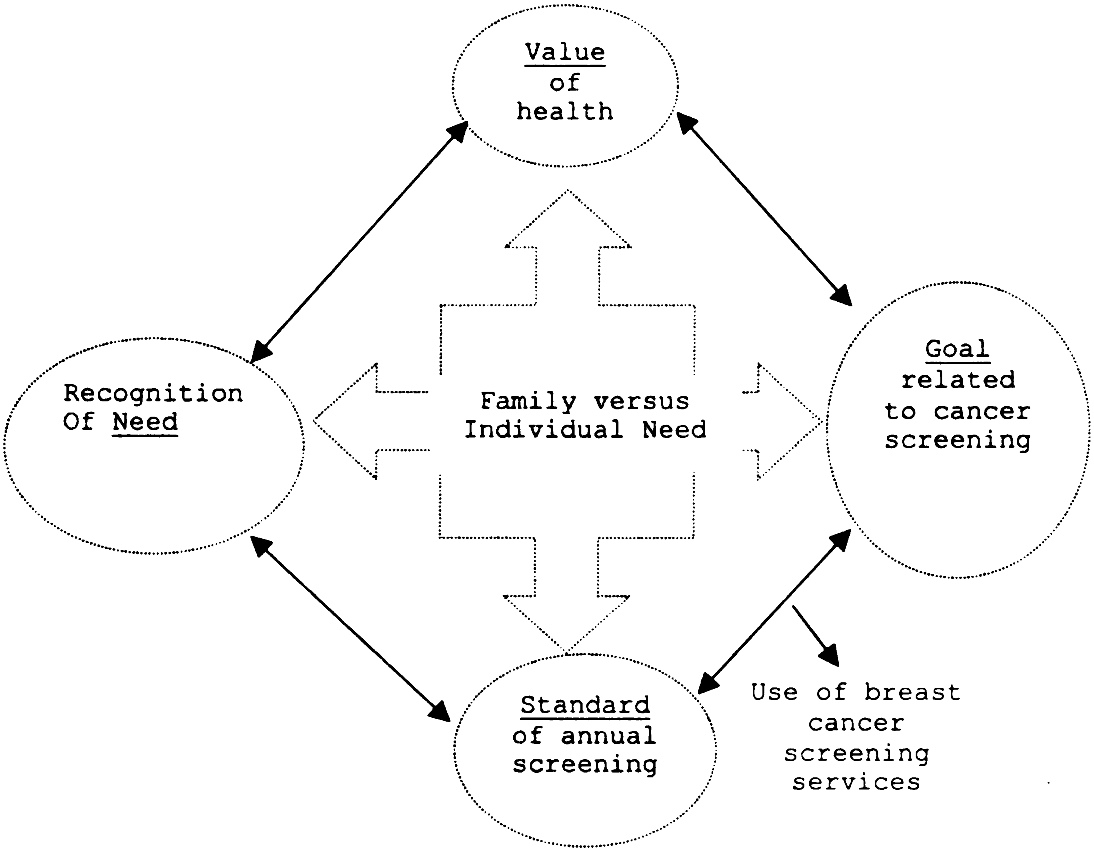


Figure 3. The Decision Making Process of Breast Cancer Screening



The individual emotional component and the recognition of need for mammogram also may be influenced by fear related to breast cancer (Bryant & Mah, 1992; Savage & Clarke, 2001). This model (Figure 3) also represents how family relationships may mitigate this fear and influence the decision-making process in a positive way.

To date, very little research has focused on the factors that facilitate participation in breast cancer screening. Using a family ecosystem and life course perspective to explore the decision-making surrounding screening may help to understand the process.

Purpose

The primary focus of this qualitative research is to explore family ecosystem and life course factors associated with health beliefs and the decision-making process related to the use of breast cancer screening services.

Objectives

The short-term objectives of this research are:

1. To explore the influence of beliefs and values about health on the decision to participate in breast cancer screening.
2. To explore the influence of life course transitions and events on participation in breast cancer screening.

3. To explore characteristics of women aged 40-55, that reflects culturally specific attributes.

Research Questions

The general research questions that guide the design of this qualitative study are:

1. How do women describe their health needs in relationship to their family?
2. Where do women learn about their breast health needs?
3. What family related factors do women consider when making the decision to participate (or not) in breast cancer screening?
4. What are the effects of life course transitions and events experienced by women on their participation in breast cancer screening?
5. How do women perceive their family relationships, life course transitions and events as influential in their decisions to participate in breast cancer screening?
6. What factors described by women in their decision to participate (or not) in breast cancer screening can be described as culturally specific attributes?

Conceptual Definitions

The following conceptual definitions relate to the research objectives, the research questions, the developing model, and the review of the literature.

Breast cancer screening: refers to a clinical breast examination (CBE) performed by a health care provider during a physical examination, and mammography. Mammography is a form of breast x-ray. The ACS (2003) recommends women forty years and older have both annually.

Decision-making: refers to a deliberate and conscious act of selecting from two or more choices into a course of action (Bristor, 1990).

Age eligible: refers to the age boundary set by breast cancer screening guidelines. For this study age eligibility refers to women who are age forty years or older because the ACS (2003) recommends annual examinations for clinical breast examinations and mammography at this age.

Culture: refers to a complex ethnographic collection that includes learned group behavior (Clifford, 1988).

Culturally specific attributes: refers to those attributes of a culture identified as individual or collective in nature (Triandis, 1995).

White: another term used to describe individuals of European descent (Smedley, 2001), at one time referred to as Caucasians.

Race: refers to a controversial and ideological term socially created to represent and structure the world, and to categorize individuals and explain differences based on racial differences and used to describe groups who share the same origin (Miles, 1993).

Individual time: refers to chronological time and focus on periods of one's life. Individual time also includes cohort time or age categories based on the time of birth (Price, et al., 2000).

Historical time: refers to societal (macrolevel) changes over time and how these changes affect the individual and family (Price, et al., 2000).

Generational time: refers to the rank order of individuals within a family and the roles/expectations associated with those positions (Price, et al., 2000).

Value: refers to something held in high esteem or deemed important (Bristor, 1990).

Goals: refers to elements of a decision that have a foundation in a value (Bristor, 1990).

Standards: refers to a measure or model for comparison. Standards indicate a degree or measure of strength in a value and sets limits of what is acceptable in working toward a goal (Bristor, 1990).

Collectivism: refers to a social pattern of linked individuals who view themselves as parts of a collective (family), are motivated by the norms and duties of the collective, give priority to the collective over their own personal goals, and emphasize their connections to the members of the collective (Triandis, 1995).

Individualism: refers to a social pattern of loosely linked individuals who view themselves independent from collective groups, are motivated by their own preferences or needs, prioritize their own goals over the goals of the collective, and emphasize the advantages or disadvantages to associating with others (Triandis, 1995).

Models

The model in Figure 1 represents a theoretical framework of the relationships between life course and ecosystem factors influencing breast cancer screening. Fluid boundaries, shown as broken lines, exist within and between each environment and the life course experiences of the individual living within a family unit.

Environed unit and life course

Individuals in this study, from an ecosystem perspective, are members of families. From a life course perspective, the participants in this study also are from the same generational time. Consequently, they may be experiencing similar life course transitions and events characteristic of mid-life. Examples of these events may include, but are not limited to, experiences such as children leaving home (normative event), divorce and other changes in the marital dyad (non-normative events), or caring for aging parents (normative event).

Social/cultural environment and life course

Within this study, the social/cultural environment includes cultural norms (beliefs and values about breast health) related to participation in cancer screening that is influenced by membership within a social group. As members of the same cohort, each of the participants has experienced a similar historical context that may influence the decision to participate in breast cancer screening. However, because of differences in race, the historical events influencing the decisions may have been experienced differently by the White and African American women.

Human built/technology and life course

The human built /technological environment in this model includes the health care system and the health care provider. While not a focus of the research questions, the human built/technology environment is an important part of the ecosystem model and may influence access to screening via health insurance, transportation, screening equipment, and facility use.

In Figure 1, a time line drawn over the ecosystem environments represents the ongoing and ever-changing influences of life course transitions/events experienced by women as they move through developmental stages. The double-headed perpendicular arrow represents the interactive effect of the family ecosystem and life course transitions on the decision to participate in breast cancer screening. Ultimately, the patient, who is a member of a family and possesses a set of beliefs that interact within a social/cultural environment, transforms knowledge that may or may not result in participation in breast cancer screening.

The conceptual framework (Figure 2) and the decision-making framework (Figure 3) represent what may be factors associated with breast cancer screening for most women. It is within the context of these models that this research will be developed. In summary, this research focuses on family ecosystem and life course transitions/events that influence women's perceptions of health and participation in breast cancer screening. This focus will lead toward a fuller understanding of the influence of family relationships versus race/ethnicity in the decision to participate in appropriate screening services.

Overview of subsequent chapters

This chapter outlined the importance of this research and introduced the research questions. Chapter 2 presents a review of the literature that examines the foundation for this research within the context of the family, cultural attributes (of individualism versus collectivism), the intersection of race, class and gender. Chapter 3 links the supporting theory and research questions with the methods used to conduct this qualitative research, including rationale for the processes employed. Chapter 4 displays and discusses the research findings. Chapter 5 summarizes the findings and provides recommendations for further research as well as limitations of this study in answering the research questions.

Chapter 2

LITERATURE REVIEW

This literature review begins with an exploration of family health, family systems and the concepts of individualism versus collectivism as cultural attributes. In addition, the concepts of race, class, and gender are reviewed to add a contextual frame of reference for examining participation in breast cancer screening experienced by women. This context is important in understanding the environments in which women interacts that influence breast cancer screening participation.

Overview

Overall, screening methods for detection of breast cancer have led to the diagnosis of early stage disease. However, barriers to screening remain for women, particularly for women with low income, low education and those from minority populations. That is, barriers to cancer screening may in part, be the result of social/cultural beliefs within the family and disparities related to the intersection of race, class, and gender.

Family health

Family health is an ambiguous concept (Denham, 1999a). While the focus of this research is not family health, it is important to understand that family members are interdependent, and the health of one individual affects the health of the family. Key findings in one study of the definition of family health and practice in a sample of Appalachian families concluded that mothers were responsible for family health, members of families participated in health routines, family health was affected by social/cultural practices and beliefs, the incorporation of health knowledge in daily routines within the family was inconsistent, and community and culture affect family health (Denham, 1999a). Within this study, families of origin played important roles in shaping health beliefs and practices. However, these beliefs and practices among children were influenced by social contexts including peer relationships, media, and teachers. Spiritual values and family traditions also affected parental health beliefs and values (Denham, 1999a).

In the same study (Denham, 1999a), families used health routines to translate individual beliefs into family behaviors. Examples of these routines included dietary practices, sleep, activity, avoidance behaviors, and medical consultation. Family members then used the health routines to "a) support developmental processes, b) avoid illness, disease, and injuries; c) attain, sustain, and regain member health; d) obtain and distribute health resources, and e) construct unique family health paradigms", (Denham, 1999a, p. 140). Family health is an important consideration in linking individual health variables with family structure, function and the context in which individuals live (Denham, 1999a).

In another study of family health among economically disadvantaged families (Denham, 1999b), households were identified as the location where family members integrated knowledge about health and health beliefs (Denham, 1999b). Within this group of disadvantaged families, members were more concerned about learning to live with medical problems, changing behaviors, accessing enabling resources, and other issues rather than increasing services related to pregnancy, having more providers in the community and getting more health knowledge (Denham, 1999b).

Family legacy is another concept to consider in understanding family health. Family legacy is a "living tradition, an aspect of the family's life world reshaped over time" that connects the family's past with its present and future (Plager, 1999). Family legacy, and the stories families tell, demonstrate how families develop meanings about family health concerns and how the family then puts those meanings into practices, habits, and activities

(Plager, 1999). These practices then act to promote or detract from family and individual health (Plager, 1999).

Understanding family legacy and the contribution family legacy makes to health choices in terms of health promotion and disease prevention may provide some understanding of participation in cancer screening.

Family and health messages

As an outcome of the autobiographical nature of this study, a review of the literature related to health communication within the family was added. Understanding health within the context of the family requires consideration of family communication. A brief review of the literature offers some insight into current views of family communication and health related factors. Fitzpatrick and Badzinski (as cited in Fitzpatrick & Ritchie, 1993) determined that the "nurturance of family members takes place primarily through the exchange of verbal and nonverbal messages" (p. 565). Both the style of communication and the content of messages vary within families and cultures. For example, variation in the style of communication occurs within individualistic versus collectivistic cultures. Individualistic cultures encourage self-expression while collectivistic cultures encourage self-censoring (Ng, Loong, He, Liu & Weatherall, 2000). Within the family ecosystem model, communication is viewed as one of the most important interactive processes within the family. As a result, information and meaning within the family and between systems occurs (Bubolz & Sontag, 1993).

Family communication patterns have been examined to determine the development of reticence among children (Kelly, Keaten, Finch, Duarte, Hoffman, & Michels, 2002). The author's studied 155 students involved in a university based reticence program to determine the influence of family communication as contributing to the development of reticence. Kelly, et al. (2002), determined that reticent individuals have families with inhibited or absent communication patterns. The author's suggest that the development of coping skills for dealing with negative emotions is prevented from developing as a result of this inhibited communication style.

Lytle, Birnbaum, Boutelle & Murray (1999) explored the context of health messages within the family and issues faced by teenage children. In a study of 309 parent and teen pairs, participants were asked to rank order various topics included in family discussions. The author's suggest that parents prioritize health topics within family communication and that those messages viewed, as low risk may not be communicated within the family or topics such as sex, may be avoided. Within this study, low socioeconomic groups of African American parents significantly discussed eating habits more frequently than White adults. The author's also noted that avoiding the discussion of health promotive behaviors during adolescents may lead to adult behavior patterns that are difficult to change.

Recent research related to health communication provides some suggestions for the development of effective health messages for women. Health communication strategies for addressing barriers to breast cancer screening among African American women were identified by Frisby (2002). The ninety-two women in this study were asked to identify risks associated with breast cancer and to determine the use of advertisements within African American publications to increase knowledge about breast cancer prevention. Results of the study revealed negative thoughts and feelings about breast cancer and little knowledge or understanding about risk factors. Frisby suggests that to persuade African American women participate in screening, advertisements of African American women role models and survivors must be used. Women in this study also suggested the use of rational advertising appeals that included causal and risk related information.

Childhood is the time when health behaviors and lifestyle patterns are established and persist throughout adulthood (Misra & Aguillon, 2001). Parents represent one of the most influential groups in the acquisition of health promotion behaviors such as eating behaviors and smoking. Misra & Aguillon (2001) studied the predictors of health behaviors in rural adolescents and concluded that nutrition and physical activity levels are under the influence of parents. The level of education of the parents predicted the dietary habits of the adolescents. The authors also stressed the influence of peer groups on health behaviors especially among females. As a result of the increase in dual career and single parent families, the author's suggest the need for enhanced health education programs in rural areas to improve levels of good health behaviors.

In summary, communication within the family is an important interactive process. Family health communication occurs differently between families. Both the style of communication and the perception of priority topics may contribute to the development of behavior patterns in adulthood. Behaviors are learned in the family and in response to peer influence. These behavior patterns may be difficult to change and may require specific strategies to promote the use of preventive methods related to breast cancer screening.

Life course and transitions

The concept of health related to life course transitions is receiving increased attention among health researchers. A life-course view recognizes the cumulative effects of factors learned in early childhood upon the production of disease in later life (Smith & Hart, 2002).

Halfon and Hochstein (2002) offer a framework for measuring health, health system design and long-term care investment in health development entitled the Life Course Health Development (LCHD). According to the authors, "the most important implication of the LCHD framework is the need to treat health development as a long-term investment". That is, focused attention on the health of children will result in improved health experiences in mid-life and old age (Halfon & Hochstein, 2002). Within the LCHD model, environments are dynamic and provide varied influences on the lives of individuals that are stage dependent. While peer influences shape the health development of adolescents, social networks and systems influence the lives of older adults (Halfon & Hochstein, 2002).

A life course perspective has been used to understand childhood gender inequality across the life course (Baunach, 2001). Using bivariate, multivariate, and cluster analysis, the author examined childhood gender inequality in preindustrial societies where childhood often does not exist or exists in a rudimentary form. The simplicity of preindustrial societies was an important consideration in examining childhood gender inequality. Using data from the Standard Cross-Cultural Sample, 186 societies were included in the study. Within this study, economic and familial factors consistently were associated with childhood inequality. While family and economics have a greater effect on childhood gender inequality, politics contributed more to adult gender inequality (Baunach, 2001).

A life course perspective lends itself to understanding the lives of older adults in retirement, grandparenting, and their economic well-being (Kim & Moen, 2002; Crosnoe & Elder, 2002; Vartanian & McNamara, 2002). Men and women undergo complex adaptation processes during the transition to retirement. Factors viewed as important in the late midlife transition, aside from financial adequacy, include personal (health) and social-relational resources (marital quality) (Kim & Moen, 2002).

Grandparent-grandchild relationships and the intergenerational dynamics of those relationships from a life-course perspective call attention to the linked lives of family members (Crosnoe & Elder, 2002). Using data collected in the Iowa Youth and Families Project, the authors wanted to know if the grandparent-grandchild relationship changed when children enrolled in higher education. The results of the study indicate that the relationships do change in a positive way. The authors also highlighted how demographic changes have increased the importance of grandparents within the family structure and on society. These demographic changes include decreasing mortality rates resulting in lengthened relationships, decreasing fertility rates limiting the numbers of grandchildren in a family, and increasing divorce rates that involves more active grandparenting (Crosnoe & Elder, 2002).

Economic well-being is a concern in later life with older women more likely to live in poverty than older men are (Vartanian & McNamara, 2002). The authors used data from the Panel Study of Income Dynamics (PSID) to examine economic outcomes across a 30-year span for a sample of women representative of the nonimmigrant US population. Midlife characteristics (workforce participation, income, and rural residence) strongly influence economic outcomes in later life. Coupled with midlife characteristics, late-life events contribute to the persistence of poverty in old age. The authors suggest that the solution of poverty among older women must include efforts to address midlife events that effect later life poverty. The heaviest concentrations of poverty in old age are those vulnerable groups of women who were previously poor, non-White, and unmarried. This suggests that older women living in poverty may also experience problems related to racism, a lifetime of poverty and the long-term effects of divorce (Vartanian & McNamara, 2002).

These studies underscore the need to consider life course transitions and events as important factors influencing the lives of individuals and families. Understanding life course transitions and events and the influence on decision making related to health in terms of prevention may provide some understanding of participation in cancer screening.

Along with family health and a life course perspective, race, class and gender provide a contextual view of factors affecting women in our culture and their ability to obtain needed health care such as breast cancer screening.

The Intersection of Race, Class, and Gender

Some authors have offered explanations for the differences in access to health care experienced by low-income women as a product of individual characteristics (Ulcickas, Yood, Johnson, Blount, & Abramset, 1999; Broyles, McAuley & Baird-Holmes, 1999; Nerenz, 1998; & Meischke, Andersen, Bowen, Kuniyuki, & Urban, 1998). Traditionally, the uses of race, class, and gender were descriptive and categorical, resulting in a labeling of individuals within family models (Collins, 1998a; & Guralnik, & Leveille, 1997) to explain differences. An intersection approach examines race, class, and gender as constructs of one another rather than as distinct social hierarchies (Collins, 1998b).

Race and Class

A history of racism and viewing racial differences as a result of biological rather than political or economic phenomena has resulted in the belief that African American family organization is a product of cultural and psychological values (Collins, 1998a). However, attributing the change in African American family structure in the past 30 years (from two parent structures to single female-headed households) global capitalist development highlights the political and economic challenges African Americans face (Collins, 1998a). Changes in industrial development patterns effect jobs that are available on American soil. Emerging evidence suggests the need to focus on gendered divisions of labor, mechanization, and global political economy as factors associated with African American and minority family organization (Collins, 1998a). These global developments influence the type of jobs minority women have that result in poor health care access frequently due to lack of health insurance.

Race and gender

Race evolved as a belief that there were biologic characteristic differences among groups of people expressed in terms of distinct, self-reproducing groups (Miles, 1993). The idea of race and the existence of these biologic differences among individuals became a common assumption in science. Consequently, the categorizing of individuals within racial groups was a common practice beginning in the 1920's (Miles, 1993). Race associated with minorities, in particular African Americans, became fashionable in the 1980's as a means of mobilizing political factions against "racial struggles" (Miles, 1993). While the biologic difference attributed to race is no longer accepted, racism in society serves as a mechanism to allocate scarce resources (jobs, welfare, health care, etc.) among individuals deemed deserving and "others" judged less worthy (Miles, 1993).

Thinking of gender in terms of patterns of differences and domination between men and women helps to understand the social construction of the concept of gender (Baca Zinn & Eitzen, 2002). Women are disadvantaged when compared to men in terms of income and education (Baca Zinn & Dill, 1994) because of traditional roles assumed by White women (caregivers of the family) that lead to an unequal power structure within families (Baca Zinn & Eitzen, 2002). Historically, White women who worked outside the home fell victim to "capital logic" geared to increase profit margins. Specifically, White women took low-paying jobs because of the perception that they were unqualified for other jobs or because women were viewed as "satisfied" with the low-level jobs. Consequently, these practices resulted in class stratification that persists today (Baca Zinn & Dill, 1994). Historically, African American women have always worked outside the home in jobs that limited access to benefits (custodians, cooks, domestic workers) (Weddle-West, 2000). Only recent changes in access to higher education have made the experience of employment for middle class African American women similar to the experience of White women. However, older African American women are less likely to be married than White women and have the economic benefits as a result of marriage (Cochran, Brown, & McGregor, 1999).

Race, class, gender and health care access

A discussion of the intersection of race, class and gender provides the background to examine barriers to health care. The discussion of race, class and gender related to breast cancer screening among underserved women includes three perspectives contributing to the disparity in access. These are historical economic contributions, societal barriers (contributing to disparity) and institutional racism. However, before discussing the intersection of race, class, and gender, it is essential to understand the current view of breast cancer screening among underserved populations and recommendations for breast cancer screening.

Breast cancer data

Socioeconomically disadvantaged populations bear the excess burden of cancer mortality and increased morbidity because poverty is associated with less access to health care and an increased incidence of cancer resulting in a lower, survival rate. Populations most vulnerable to late stage diagnosis and death because of breast cancer include African American women (31.4 per 100,000) compared with

White women (25.3 per 100,000) (ACS, 2001b). While the incidence rate for newly diagnosed cases of breast cancer is 13% lower in African-American women than White women, breast cancer remains the second leading cause of cancer death for African-American women. In addition, breast cancer death rates among African American women are 28% higher than among White women. Whether this difference is attributable to late stage diagnosis or tumors that are more aggressive is unclear (ACS, 2001b).

Breast cancer screening

The goal of breast cancer screening (clinical breast exam and mammography) is to discover cancers early when cure is more likely and treatment is less traumatic (Caplan, 1997; Kerlikowske, et al., 1995; Stowe & Schumann, 1999). Women from lower socioeconomic groups or those without private insurance are less likely to receive comprehensive breast cancer screening (Mikey, et al., 1997; Ayanian, et al., 1993).

Because of increased use of mammography, breast cancer incidence rates steadily increased from 1982 to 1987, with a stabilization of rates in recent years (ACS, 2001c). Mammogram usage increased from 27.4% in 1987 to 68.9% in 1998 among women reporting a mammogram within the previous two years. Within Michigan, the percentage of women reporting having had a mammogram within the past year (recent mammogram) included 65.8 % of women aged 40+, 66.9% (aged 40-64), 70.2% (aged 50+), and 63.7% (aged 65+ years). The percentage of women reporting having had a recent mammogram and a clinical breast exam aged 40+ was 60.4%, 62.3% (aged 40-64), 63.6% (aged 50+ years), and 56.6% (aged 65+)(ACS, 2001c). Variability in mammography use (mammogram within the past two years) occurs among women over the age of 40 by race (Whites, 68%; and African Americans, 66%)(ACS, 2001c). The data indicate a need to maintain or improve breast cancer screening, especially among African American women.

An Intersection Approach to Breast Cancer Screening

An explanation for the disparity in breast cancer screening experienced by African American women when compared with White women may be evident through an examination of the economic status of women. An intersection approach lends itself to viewing the disparity as a result of the economic status of women rather than characteristics of the women who are eligible for the service.

Historical economic contributions to access disparity

Women of color traditionally receive the lowest wages, perform the worst jobs, or are unemployed (Baca Zinn &

Dill, 1994). Historical factors associated with the economic strains experienced by white women include low work force participation, less work experience, and less education (White and African American women). These issues contribute to fewer resources for women in terms of social security, pension accounts and personal savings and less access to the best health insurance.

The economic disadvantages experienced by African American elderly women relate directly to their working lives because they were more likely to be poorly educated and hold low paying jobs. Also, job discrimination may be a factor determining the types of jobs African American women were able to obtain (Ozawa, 1995). As a result, women of color are less likely to have access to the best health insurance and more likely to have no health insurance or insurance through the Medicaid/Medicare system. This represents societal rather than individual barriers to access. Even among married women, variability in employment of the spouse may contribute to inconsistent access to sources of health insurance (Rubin, 1994).

Societal barriers contributing to access disparity

The breast cancer screening literature clearly identifies not having a regular health care provider and as poor provider communication as barriers to access. Viewed as a function of the larger society, these factors indicate the effects of discrimination and poverty (Baca Zinn & Dill, 1994).

Racial differences in access to health care (from a historical and societal perspective) may provide insight into the disparity experienced by minority women as related specifically to employment. Women, and particularly minority women, historically have been the victims of discriminatory practices in employment, a form of institutional racism. Not having health insurance because of unemployment is one barrier to recommended screening procedures. The lack of access to employment and cancer screening may be related to institutional racism.

Institutional racism contributing to access disparity

Franklin (1991) describes the application of institutional racism and the resultant dominant/subordinate nature of institutional racism as affecting the roles played by African American and Whites in the work place. Institutional racism implies three ideas. One, there is a dominant group with power over another group and an ability to affect their means. Two, color is pejorative to the dominant group. Three, there is a sense that behavior exhibited by African Americans and Whites is evaluated differently (Franklin, 1991). Through institutional racism, there is an appearance of integration among African Americans and Whites because they work in the same location. Yet, under institutional racism few African Americans experience upward mobility, and many find themselves locked in lower level jobs (Franklin, 1991).

There is evidence of institutional racism toward African American women. In the United States, citizens receive rights and responsibilities from group membership (e.g., old age pension, social welfare, and free public education). Race is constructed along bloodlines, with members of racial groups experiencing differences in the distribution of these rights (because of racial segregation that reproduce social inequalities). As an example, African American women experience differences in the entitlement criteria for Social Security resulting from institutional racism and gender-ideology. That is, race was a factor used to exclude occupational categories covered by Social Security. These included agricultural and domestic workers, occupations often held by African American women. Consequently, African American women experience less access to income and benefits (Collins, 1998a). Therefore, African American women experience institutional racism in two ways. First, because they occupy low-level jobs with poor benefits, they have less access to health insurance. Second, because they do not receive Social Security benefits, they have less access to income needed to pay for health care.

Institutional racism is one explanation for the disparity in access to breast cancer screening experienced by women in minority groups. In addition to having less access to jobs with adequate health insurance benefits, the health delivery system itself practices a form of institutional racism. The organization of health delivery systems is such that providers are dominant and patients are subordinate. Add to that the fact that the majority of providers are White and male, and the dominant/subordinate nature of health care is even more pronounced. While African Americans will purchase services from White professionals (Franklin, 1991) it is unclear if minority women are reluctant to seek health care advice about personal matters (such as breast care) from a group of individuals historically viewed as oppressors.

Reasons for the disparity in access to breast cancer screening relates to access to adequate health insurance, a direct result of poor access to high paying jobs. Women with low income are less likely to have access to a regular source of health care and are less likely to afford out-of-pocket costs of obtaining comprehensive care. The literature would suggest that White women would participate in screening with fewer issues. An exploration of the social origins of race and the concepts of individualism and collectivism may be beneficial in understanding the differences experienced by White and African American women.

Social origins of race

While the purpose of this research is not a thorough exploration of race it is important to understand that race is socially and historically defined. Groups typically identified as White (Irish) were described as barbaric and savages. Africans came to the colonies as early as 1619 with their position in society similar to other servants, evidence of a lack of a uniform attitude toward Africans. All servants and all poor, regardless of color, were treated badly and were exploited in colonial America (Smedley, 2001).

Colonial leaders were the first to separate the European poor from Africans and Indians as a way of creating a buffer between classes of people. This first division set the precedence for the ideology of race. Although gradual in nature, the institutionalization of slavery resulted from the self-interest of European Americans whose focus was the development of wealth

(Smedley, 2001). As described by Peter Fryer, "Racism emerged…in Britain in the eighteenth [century], as the ideology of the plantocracy, the class of sugar-planters and slave-merchants that dominated England's Caribbean colonies. It emerged, above all, as a largely defensive ideology--the weapon of a class whose wealth, way of life, and power were under mounting attack" (Smedley, 2001, p. 15).

Myths about Africans as a distinct race emerged as a rationalization for slavery (Smedley, 2001) with the physical characteristics of Africans as indicative of an inferior class of people. Race, therefore, began as a "folk" idea rather than a derivation of science.

Goodman (2001) described six reasons why racial science is wrong. It is the sixth reason that is most pertinent for this research. That is, conflict exists between biology and lived experience. Underlying reasons for racial differences in health (environmental exposures, access to medical care, diet) often go ignored. Conditions of life rather than racial differences must be examined rather than using race as a proxy for health variations (Goodman, 2001).

"Whiteness"

The category "White" describes the majority culture and norms within the United States. Yet, few White people see themselves as White or can articulate the attributes of "Whiteness" that contribute to the norm (Dutton, Singer & Devlin, 1998). Understanding the experience of non-Whites requires an awareness of the racial attitudes of Whites and feelings of Whites (Parker, Moore & Neimeyer, 1998) that may influence the process of participation in screening.

Helms (1984) found that members of the White majority culture could better understand the experience of others if they understand their own racial identity. The staged development of racial identity begins with the first stage of *contact* that is marked by a naïve view of oneself as a racial being and color-blind attitude about racial differences. The second stage is *disintegration*, which involves an awareness of the implications of race (sociopolitical), and the benefit experienced by Whites as a result of being White with fear about not being accepted by those who benefit from racism. The third stage involves *reintegration*, characterized by anger toward African Americans, denigration of blackness and an idealized vision of those things perceived to be White. The fourth stage is the *pseudoindependent* stage, characterized by an intellectual understanding of African Americans with acceptance of those who seem to be like Whites. *Autonomy* is the final stage, with Whites internalizing a positive and non-racist self-identity and an appreciation for cultural similarities and differences. Involvement in interracial interactions is also a characteristic of autonomy (Helms, 1997).

While beneficial in stressing the importance of understanding White racial identity and the benefits afforded by group membership, intragroup differences remain obscure. Certainly, the data suggest that White women are more apt to participate in cancer screening and to receive early stage cancer diagnoses. Yet, there are women who fall outside the norm, including women with both high levels of education and income. This suggests family ecosystem and life course experiences may influence the decision to participate in screening. The importance of this idea is to focus attention on factors other than education, income, and minority group status that affect breast cancer screening, to adequately address the needs of individual women. These factors may include issues related to gender and roles of women within the family.

White women and family roles

In the United States, the traditional family is described as a married couple with children (Giddens, 2003). Prior to the industrial revolution, the family was an economic unit that functioned to support an agricultural economy. As part of this family structure, inequality among men and women existed, with women having few rights (Giddens, 2003). Sexuality was predominately a function of reproduction. Victorian norms regulated women's roles--virtuous, subservient, and unequal to men (Giddens, 2003). While women's roles have changed, inequality related to gender in American Society remains. Jackson (2003) provides examples of this inequality ranging from inequity in employment opportunity to inequity in laws. Few women hold high political offices and the "glass ceiling" in employment continue to exist. Prestigious fields, like higher education, are largely male oriented. Costs for women in divorce exceed costs for men. Women experience sexual harassment and fear of rape remains even with laws to control both. Finally, there exists a cultural image that perceives men and women as different (Jackson, 2003).

Black women and family roles

Historically, the African American family is a product of slavery. The prevailing family structure during slavery was conjugal and helped to provide stability (Weddle-West, 2000). As described by McCray in the article by Cochran, et al., (1999), African American women have held multiple roles in the family. These roles can be attributed to African cultural heritage, religious beliefs, caretaking roles resulting from socioeconomic barriers, and factors associated with family preservation. African American women have worked to contribute to family income and care for relatives and fictive kin. As a result, large numbers of multigenerational families exist in African American communities (Cochran, et al., 1999).

Culture and differences

Understanding cultural differences within and among groups is difficult. Sowell (1994) believes the difficulty arises from the fact that "Cultures involve attitudes as well as skills, languages, and customs. Attempts to measure cultural differences between groups by attitude surveys…miss the crucial point that culture is expressed in behavior, not lip service" (p.10). Groups' values related to culture become evident in the choices that are made and the sacrifices actuated in reaching the goal (Sowell, 1994).

Sowell (1994) also believes that distinctive characteristics of a group are separable from identity with the group. Individuals who do not have direct cultural roots or connections with the social experience of the group take on an exaggerated kinship with the group (Sowell, 1994). That is, it is…"a common social phenomenon around the world that those who have lost a culture have often been its most strident apostles" (Sowell, 1994, p. 28). Serious social consequences that arise from exaggerated cultural identity include the danger of leveraging extreme fringes within a group, and inhibiting the cultural advancement of "lagging" groups. As a result, negative consequences include differences in education, income, and other social factors (Sowell, 1994).

Collectivism versus individualism

Triandis (1995) describes culture in relation to society as memory is to individuals. Within this context, societies use what has worked in the past as a tool in the same way that individuals use memory. Tools that become part of culture include shared beliefs; attitudes, norms, roles and values, and these tools form a subjective culture (Triandis, 1995). Implicit within this idea of culture are "unstated assumptions" that "…we are bound together into tight groups of interdependent individuals is fundamental to collectivism…and that we are independent entities, different and distant from our groups, is fundamental to individualism" (Triandis, 1995, p. 4). Broadly, cultural differences may be related to whether a culture is collective or individual.

Collectivism is a "social pattern consisting of closely linked individuals who see themselves as parts of one or more collectives (family, co-workers, tribe, nation)" (Triandis, 1995, p. 2). As a result, personal goals are overlooked in preference for the goals of the group. Individualism is a "social pattern that consists of loosely linked individuals who view themselves as independent of collectives (Triandis, 1995, p. 2). The focus of individualism is the personal needs, rights and desires of the individual over the group.

The research toward defining collectivism and individualism has become more complex (Westerhof, Dittmann-Kohli & Katzko, 2000). Typically, in cross-cultural research, cultures are characterized in terms of values where aggregates of individuals become the unit of analysis (Westerhof, et al., 2000). From this perspective, cultures become a statistical average of the individuals (in the aggregate) and receive a value based on that average, such as, a culture of individualism versus collectivism. Culture (taken as a statistical average of an aggregate of individuals) becomes an independent variable influencing an individual. Analysis of individuals within a culture reveal "meaning within individuals" that cannot be revealed through statistical methods (Westerhof, et al., 2000). Therefore, individuals and culture are inseparable. In this manner, culture is realized through individuals and individuals experience their lives through acculturation (Shweder & Sullivan, 1993). As described by Westerhof, et al., 2000:

> It follows that if one wants to understand in more detail what individualism or collectivism might mean, one needs to examine the unit of reality wherein that attribute lies: within the individual. This allows us to be more explicit both about the "statistically average" meaning of the term, as applied to the aggregate, while at the same time being able to point to the richness of meaning of the attribute as assigned to the object of study within which it resides: a bottom-up focus on the individuals as the unit of analysis (p. 651).

Historically, African societies are collective and the U.S. society is individualistic (Triandis, 1995). The extent that a collective view of culture among African Americans and an individualistic view among Whites in the United States influence decisions related to health care is unknown. Lukwago, Kreuter, Bucholtz, Holt, and Clark (2001) have developed a brief scale to measure collectivism among African American women related to colorectal cancer screening. The authors (Lukwago, et al. 2001) suggest that collectivism is associated with health-related beliefs. Through an understanding of collectivism as a cultural attribute, researchers might develop interventions that are more appropriate to address health disparities (Lukwago, et al., 2001). Rather than using a scale to measure collectivism versus individualism, this research will explore whether or not women express individualistic or collective attributes in describing their decision whether (or not) to participate in breast cancer screening.

Summary

The literature demonstrates that membership in racial/ethnic groups and women who lack health insurance coverage are more likely to be diagnosed with late stage breast cancers than White women with higher education levels and higher incomes. While breast cancer screening rates have improved, underserved women continue to face barriers to regular screening.

Barriers to cancer screening such as lack of health insurance, a regular source of health care, knowledge, and transportation have been mitigated through a variety of programs. However, disparities in access to appropriate screening services remain among underserved populations. Viewing the context in which cancer screening occurs while considering the role of race, class, and gender offers some insight into the ongoing disparity despite improved screening programs.

Family health and women as the guardians of health within a family provide some understanding of how health information is disseminated with the family system. Little is known about the influence of family ecosystem factors associated with cancer screening participation. Even less is known about the influence of life course transitions and events experienced by women and their decision to participate in screening.

Finally, we know little about the influence of cultural attribute differences (in terms of collectivism and individualism) related to breast cancer screening. Improving breast cancer screening is a complex task. Therefore, this research will explore family ecosystem and life course factors associated with breast cancer screening and evidence of cultural attributes (collective versus individual) among White and African American women.

Chapter 3

RESEARCH METHODS

Research Design

The purpose of this qualitative study was to explore family ecosystem and life course factors associated with perceptions of health and breast cancer screening. This study used a case study approach to gain a better understanding of the experience of White and African American women and their participation in breast cancer screening. Congruent with this purpose, the research questions introduced in Chapter I include:

1. How do women describe their health needs in relationship to their family?
2. Where do women learn about their breast health needs?
3. What family related factors do women consider when making the decision to participate (or not) in breast cancer screening?
4. What are the effects of life course transitions and events experienced by women on their participation in breast cancer screening?
5. How do women perceive their family relationships, life course transitions and events as influential in their decisions to participate in breast cancer screening?

6. What factors described by women in their decision to participate (or not) in breast cancer screening can be described as culturally specific attributes?

Data collection was conducted using case studies. The case study is bounded with patterned behavior (Stakes, 2000). This boundary presents the opportunity to learn something specific about the participants described in the case study. The sample consists of ten women aged 40-55 years who are employed and have health insurance and have a minimum of a high school education. Participants examined their experience with health, breast cancer screening and the relationship between their screening experience and family ecosystem factors, life course transitions and events within their family of origin and their current family.

Population and sample

Participants in this study were solicited through a variety of means including contacting teachers, professionals, and acquaintances of the researcher. The rationale for soliciting in this manner was to draw from groups of women who have a higher level of education, have higher income levels, and access to health insurance in an effort to avoid factors associated with low screening participation (low income and low education)(Mikey, et al., 1997). It is believed that the experiences shared by these women should reflect family ecosystem, beliefs, and life course factors rather than factors associated with economics and education.

Participants in this study share *current* similarities in life experiences (in terms of employment, income, and insurance) and exposure to media representations of political views and current world events that may influence decision-making. None of the women in this study were raised in the same family or community.

Site of the study

The location of the study was Kent County and the surrounding community, in western Michigan. The county has a population of 560,000 people and a racial/ethnic distribution of 83% White and 7.9% African American (Census data, 2000). Each participant deferred to the recommendation of the researcher for location of the interview. The location was selected based on access to facilities that would afford privacy, comfort, and convenience. As a result, five of the interviews were conducted in a church. The church was a familiar location for the participants, it was easily accessible, and was available for use without charge. The other five interviews were conducted at a private health facility during non-business hours.

Sampling procedures

Purposive sampling techniques were used to select initial participants. Purposive sampling, ensures the researcher of getting participants who have the specific characteristics of interest in the study and who are willing to discuss the topics. The sampling is not concerned with generalizability or representativeness, rather in understanding "the conditions under which a particular finding appears and operates" (Huberman & Miles, 1998, p. 204).

A list of potential participants was constructed based on study criteria snowball techniques for all participants. The criteria for the sampling included age (40-55 years), race/ethnicity (5 White and 5 African American), gender (women), education (total years), marital status (married, divorced, single), children (currently or previously living in the home), and insurance (commercial or private). As it turned out, the researcher was acquainted with all participants, either due to a friendship or past working relationship.

Participants were contacted twice. The first contact was by telephone or in person to discuss the nature of the research, issues related to confidentiality and anonymity, and possible dates and locations to conduct the interview. Before the interview, a follow-up call was placed to confirm the time, date, and location and to determine the participant's willingness to continue.

Data collection and procedures

Each participant completed a consent form (Appendix A) designed to explain the rights of the participant as a research subject and to obtain consent for audiotaping, and for the use of direct quotes. Each participant was coded for anonymity with a pseudonym and is referred to throughout the study with the pseudonym. The researcher conducted all interviews, the interviews were strictly voluntary in nature, and the participants were not paid for their time.

After obtaining approval from the University Committee on Research Involving Human Subjects (UCRIHS), participants were recruited and interviewed. Each interview took one to two hours to complete. All but one of the interviews was completed in one session sitting. At all times, participants had an opportunity to discontinue the interview or to refuse to respond to particular questions. All interviews were conducted in English.

Because of the nature of the questions, there existed the possibility of participants experiencing social embarrassment in disclosing names. Therefore, each participant had written and verbal assurance that the data only would be presented only in coded format and that the researcher would clarify with the participant any perceptions recorded. Each participant will receive a copy of the findings as a way of acknowledging her important role in the research process.

The primary methods of data collection were semi-structured interviews and ecomaps. Unlike structured or unstructured interviews, the semi-structured format allows the researcher to ask a set of specific questions and explore responses using probes. The role of the researcher becomes somewhat directive (Fontana & Frey, 2000) using this methodology. In a structured interview, the interviewer asks a series of questions with limited response categories, leaving little room for variation in the response. The structured interview is used to capture precise information for ease in coding. In the unstructured interview, the respondent is asked to tell a story or respond to an open-ended question without further direction from the interviewer. In the semi-structured format, the interviewer listens for opportunities to explore an idea or thought in greater depth while asking the same key questions of all respondents. The semi-structured format requires the researcher to be attentive and an active listener in directing the flow of the interview session.

Ecomaps (Appendix B) allow the participants to identify relationships within their lives. Unlike a genogram that depict families over time, an ecomap pictures families spatially (Hodge, 2000). For example, respondents were asked to identify their relationship to the categories such as church, work and employer, listed on the ecomap, in terms of how those categories act as support systems, also the type of relationship, and the directional flow of that relationship. Most of the respondents had never used an ecomap so they were allowed to ask questions for guidance in the use of the key. Respondents also were given the opportunity to add additional categories if necessary. Completed ecomaps demonstrate systems and relationships that are important to the family and the character of the relationships (Hodge, 2000). The researcher used this information to further explore the effect of the relationships on the decision-making process.

Each interview was audio-recorded using standard cassettes and transcribed verbatim, by a service hired by the researcher. In addition, the researcher listened to each interview and compared the audiotape with the written version. Confidentiality was maintained by using the chosen pseudonym as a descriptor in conversion and when coding the tape for identification purposes. For example, on the audiotape label, each participant was first described with a letter denoting White or Black (W or B), a number (01 through 05) and the pseudonym (W01 Bambi, B01 Coffy). No discrepancies between the transcribed and audiotaped versions of the interviews were noted. Participants were informed that in the analysis of the interviews that they might be contacted for content clarification. The original audiotapes will be kept in a locked cabinet for three years, and all copies of audiotapes used in the transcription process were destroyed.

In addition to the semistructured interview, the researcher made field notes concerning the interview context. The notes recorded the affective state of the participant and any nonverbal responses to questions that were not recorded with the audiotape. The field notes were recorded and completed immediately following the interview.

Instrumentation

Although the interviews were conducted using a semistructured format, a protocol of core questions guided the interview (Appendix C). The interview questions were organized under the headings of family of origin, current family and reflection. Under the family of origin category, participants were asked to reflect on their family of origin when answering the questions. Under the current family category, participants were asked the same questions, but were asked to think about how the questions apply to their current family. Finally, within the reflection category, participants were asked to compare and contrast how their experiences in their family of origin differed from their current life experience. The use of open-ended questions fostered individualized participant responses. Researchers use open-ended questions to elicit responses that allow participants to describe their world in their own words (Fink, 1995). The guide served to direct the interview and to ensure that all questions needed to meet the research objectives were asked.

Each interview started with casual dialogue and a review of the purpose and expectations of the interview. Time spent in casual conversation was minimal in all cases because the researcher was acquainted with each participant. The participant was encouraged to provide expanded responses to the questions.

Qualitative data recording, management and analysis

Each audiotape was transcribed using a professional transcription service. The original audiotapes were dubbed and the dubbed versions were used by the transcriptionist. Confidentiality was maintained by coding each audiotape with the participant's pseudonym and the researcher's contact information. No reference to the participant's real name was made within the interview.

After transcription, each interview was transferred to a qualitative analysis program (Qualitative Solutions & Research NUD*IST Vivo). The QRS NVivo program was selected because of its reported ability to edit, visually code, and link documents during their creation, coding (See Table 1 for coding schemes), filtering, management and searching. Field notes were entered in the system as a memo document under each participant's pseudonym. Ecomap data were entered as attributes for each participant and coded with the participant's pseudonym. Attributes appear within the program as an aggregate table by participant. Each participant was represented within the QRS NVivo program, as a set comprised of the interview, field note memo and ecomap. The coding process began with the first transcribed interview and progressed when each subsequent interview was transcribed.

The initial coding scheme (Table 1) was based on the conceptual model and research questions. Within the QRS NVivo program, a variety of approaches to coding can be used. For this study initial coding involved broad-brush coding (Bazeley & Richards, 2000). Broad-brush coding is the first step in the process of coding, where broad areas of data are coded into nodes (family ecosystem, life course, cancer related). Then the broadly coded nodes were recoded into finer distinctions (discussions, decision-making, health beliefs). All of these nodes were reviewed and coded again into even finer categories (access issues, topics of discussion, adages, sayings, and home remedies, knowledge, beliefs, values). The QRS NVivo system allows coding under nodes that are later grouped under trees. Initially, in the broad-brush coding there were over 100 nodes that eventually were organized under the twenty trees or coding schemes identified in Table 1. The data were explored for emerging patterns and themes that will answer the research questions.

Table 1

Coding schemes

Family of Origin Codes
FOH=Family of origin health FOBC=Family of origin breast cancer FOHD=Family of origin health discussions FOBCD=Family of origin breast cancer discussions

Current Family Codes
CFH=Current family health CFBC=Current family breast cancer CFHD=Current family health discussions CFBCD=Current family breast cancer discussions

Life Course Codes
LCTFOA=Life course transition family of origin LCTCF=Life course transition current family

Family Relationship Codes
FORHD=Family of origin relationships health decisions FORBCD=Family of origin relationships breast cancer decisions CFRHD=Current family relationships health decisions CFRBCD=Current family relationships breast cancer decisions

Reflection Codes
FoCfHD=Family of origin current family health decisions FoCfBCD=Family of origin current family breast cancer decisions

Cultural Attributes
FOHB=Family of origin health beliefs FOBCB=Family of origin breast cancer beliefs CFHB=Current family health beliefs CFBCB=Current family breast cancer beliefs

Ecomaps were entered as document attributes and coded using the same coding scheme. Triangulation was accomplished using both the interview and the ecomap for data collection to confirm the information obtained from the respondents. Tapes were listed to by the researcher and compared with the transcriptions. Field notes were reviewed and compared with statements made by the women. The field notes demonstrated that the recording of non-verbal responses confirmed what the women said especially when discussing "taboo" topics with their mothers, like breasts.

Qualitative Research

Role of the researcher

Marshall & Rossman (1999) suggest that qualitative research requires consideration of participantness, revealedness, intensiveness/extensiveness, and focus of the study related to the role of the researcher. Participantness refers to the degree of actual participation in the study by the researcher. The researcher conducted all of the interviews and completed the analysis.

Revealedness refers to the extent to which a study is known to the participants. The role of the researcher and the purpose of the study were known at all times throughout the study to all participants.

Intensiveness/extensiveness is the amount of time spent in the setting on a daily basis. The setting in this study is defined broadly in terms of the location (county) where the sample is selected and the actual location where the interview takes place. Therefore, the extent of time the researcher spends in the setting is limited to the time it takes to complete the interview. For this study, participants deferred to the researcher for suggested settings, with some selecting the same setting.

The role of the researcher depends upon the focus of the study. The focus of this study is case specific and intrinsic. This type of study is used because a case in itself is of interest rather than attempting to understand an abstract concept or build theory (Stakes, 2000). In a case study, the researcher looks for the particular nature of the case. In this study, each participant represented a case with similarities and differences to each of the other cases.

Objectivity, validity and generalizability

A "reconceptualized" vision of critical theory criticizes rationalistic scholars as obsessed with issues of technique, procedure, and correctness while forgetting the humanistic aspect of research (Kincheloe & McLaren, 2000). By taking this rationalistic approach, fact is separated from value with a resultant loss in understanding the value choices involved in the factually described situation (Kincheloe & McLaren, 2000). However, even when using a qualitative approach it is necessary to examine the objectivity, validity and generalizability of the data collected.

Objectivity

Polit and Hungler (1995) define objectivity as "a desired quality of research using the scientific approach; refers to the extent to which two independent researchers would arrive at similar judgments or conclusions" (p.648). While objective approaches use conceptual categories derived by researchers to structure the analysis, subjective approaches use the participants' own constructs to frame the study (LeCompte & Preissle, 1993).

Qualitative research requires the observer to recognize and acknowledge subjectivity—conscious and unconscious sources of bias (Jansen & Peshkin, 1992). Rather than denying bias, the qualitative researcher brings these biases forward to understand them as part of the methodology while acknowledging them when drawing conclusions from the collected data. Recognizing and reflecting on personal biases (that result from personal experience) when reporting data contributes to a higher degree of accuracy in qualitative research (Jansen & Peshkin, 1992).

Researcher bias and assumptions

From a qualitative viewpoint, it is important to acknowledge my personal biases. I grew up in a family in which health services were used in response to illness or injury. My family of origin always had health insurance, so I never experienced making decisions about the use of health care based on cost related factors.

While we never discussed health as a concept, I grew up knowing that I should eat "healthy" (although that was not clearly defined), that cleanliness was important (although I didn't know why), and that I should go to the dentist (hating every moment of the visit). I also remember getting vaccinations, receiving the first polio vaccine, and getting fluoride treatments. The polio vaccines and fluoride treatments were conducted as citywide efforts to combat what I now know to be public health issues. These programs were offered through the elementary school systems, leading me to believe that they were age based programs. In my family of origin, my mother was the gatekeeper to the health care system. I have no memory of my father's involvement in health related decisions.

From the sixth grade through adolescence, what I learned about breast "health" was not from my mother, but from school films and peers. I remember learning about physiologic function of the breast as a method to feed babies and the sexual function of the breast from my friends. Breast health and breast cancer were not topics of discussion in my family of origin.

My first memory of cancer was my paternal grandfather dying of lung cancer and having oral cancer. I distinctly remember the way his lips looked and the terrible cough that he had. I do not remember feeling threatened or afraid of cancer from this experience, and I have little memory of my parents' response to his death.

My second and most vivid memory of cancer was a classmate in the first grade. She had cancer of the bone in her upper arm. I remember adults talking about how the cancer was found (she was hit in the arm with a softball) and that her arm was amputated. I can still visualize her entering the bus after the amputation, with only one arm. Again, I don't remember feeling threatened or afraid, but I do remember feeling curious. I also remember feeling sad, not because I missed her, but because everyone else was sad.

My third and most memorable exposure to cancer as a child was my grandmother's second husband who died of pancreatic cancer within two years of their remarriage. I remember feeling sad because my grandmother felt so alone, but I did not feel afraid.

All of these cancer-related occurrences contributed to vague and superficial discussions about cancer in my family of origin. I remember my mother saying, "You know if someone has cancer and they open them up to the air, the cancer will just spread". I remember my first fear in relationship to this comment; the fear of hopelessness.

In my family of origin, there was no discussion of prevention and screening related to cancer except in the use of chewing tobacco as a cause of cancer. I also have memories of my mother going to the doctor for "women's" health, but I never knew what that meant. I remember that I felt uncomfortable discussing "female" issues with my mother, so my knowledge base came mostly from my peers.

It was not until I was an adult and had finished nursing school that I gained awareness and eventually a level of expertise about cancer screening and prevention. My mother's diagnosis of breast cancer made the topic of cancer more relevant in my current family. She cared for my children on a regular basis through her treatment, so my daughters asked questions and were included in discussions of cancer. I remember feeling angry with her doctor for failing to biopsy her lump for four years; angry at my mother for not insisting that the lump be biopsied; and, angry at myself for somehow failing her. I also became aware of whom she included in her "consultant" support system and decision-making process. It was my father and her doctor. I don't know if she discussed this with her friends, but I know that she never discussed this with my sister or myself; not wanting to "bother" us.

All of these memories were present in my thoughts as I approached this research. With these thoughts in mind I made some assumptions about the women I would be interviewing. I assumed that all would have experienced at least one person having cancer in their family of origin, providing them with some memory of how cancer was discussed and dealt with, and who was involved in the decision making process. I also assumed that women would be the gatekeepers for health related decision making within the families of origin, but that in their current families, the health related decision making would be mutually shared with spouses or significant others. I assumed that each woman bring memories from their families of origin that were beliefs about cancer and that cancer may or may not have been feared. I also assumed that even though these women had health insurance, they would still take into consideration family relationships in making the decision to participate in breast cancer screening. I assumed that family relationship considerations would include scheduling and procrastination rather than cost (among individuals who did not consider screening) and participants who screened wished to identify cancer early and be "around" to see their grand children grow.

These biases and assumptions were present in the thought processes used to develop the research questions. As will be described in Chapter IV, some of my assumptions were appropriate and some were not.

Validity and generalization

Polit and Hungler (1995) limit the definition of validity as the "degree to which an instrument measures what it is intended to measure" (p. 656). Others refer to validity as the trustworthiness of inferences drawn from the data (Eisenhart & Howe, 1992). Shavelson (1996) expands the definition to mean "the extent to which the interpretation of the results of the study follows from the study itself and the extent to which the results may be generalized to other situations with other people" (p. 19). Generalizability refers to the "degree to which the research procedures justify the inference…the inference that the findings can be generalized from the sample to the entire population" (Polit & Hungler, 1995, p. 642).

In qualitative research, internal validity refers to the justification of causal relationships (Johnson, 1997) and the mutual understanding of the meanings of conceptual categories between the participants and observer (LeCompte & Preissle, 1993). Threats to internal validity in qualitative research (as in quantitative research) include history (changes in the social scene studied) and maturation (changes in individuals). Because the interviews were conducted in one session, history and maturation were not issues in this study. Methods triangulation (more than one method of research) and data triangulation (the use of multiple sources of data in a study) improve internal validity in qualitative research (Johnson, 1997). The use of data triangulation in this project should insure internal validity. Mutual understanding of the meanings of conceptual categories between the participants and the researcher was achieved using ecomaps. During and after the completion of the ecomaps, participants were asked to validate their descriptions rather than the researcher making assumptions about their intent.

When discussing generalizability related to qualitative research, four constructs affect the credibility of studies for cross-group comparisons. These constructs include selection effects (constructs specific to a single group); setting effects (constructs developed that are a function of the context under investigation rather than the context itself); history effects (effect of unique historical experiences on some groups and not others); and, construct effects (differences in meanings and terms among different groups) (LeCompte & Preissle, 1993).

Firestone (1993) suggests that there are alternative arguments for generalizing from data applied to qualitative research. One of these alternatives is the case-to-case transfer where an idea is adopted from one setting to another. Four criteria (material facts, appropriateness, reason for the decision, and generality of the decision) are used as precedents to compare with the current case. If the idea fits (material facts), seems fair or right (appropriateness), the use of the idea is reasonable for the case (reason for the decision), and the precedent decision was fundamental (generality of the decision), then generalizing is possible but the burden of responsibility for generalizing falls to the reader.

It is not expected that the findings from this study will be generalizable, but rather used to develop further research and understanding of health related decision making and implications for breast cancer screening. However, it is also expected that the cases studied will have enough similarity when applying case-to-case transfer concepts and the readers may find similarities in their own experiences.

In this research, objectivity involved the use of a conceptual model as a framework to compare the qualitative responses of the participants. From the conceptual framework, coding schemes were designed and the data were coded. Validity from a qualitative sense was addressed by obtaining participant opinions and using verbatim descriptions. In summary, researchers have options for ensuring the defensibility of qualitative research by attending to qualitative definitions of objectivity, validity and generalizability.

Summary

While medical literature abounds with quantitative descriptors of participants in breast cancer screening, little is known about family ecosystem and life course factors associated with the health related decision to participate in breast cancer screening. Qualitative methods provided an option for exploring these factors within the context of the meaning of health, cancer and screening on the part of the patient. Clearly, well-constructed qualitative research is objective, valid, and generalizable when paying close attention to adequate descriptions of the participants involved and identification of investigator biases. In this study, qualitative methods provided a unique opportunity to explore health and breast cancer screening among a selected group of White and African American women related to family ecosystem and life course factors.

Chapter 4

RESEARCH FINDINGS

This study explored the influence of learned behaviors on health decision-making in the context of life course events and the family. These learned behaviors result from family beliefs and values about health with implications for the use of breast cancer screening. By defining culture, in this study, as "a complex ethnographic collection that includes learned group behavior (Clifford 1988)", each research question seeks to understand the health related behaviors learned within the family of origin that influences current behaviors. These health behaviors may in turn affect the use of breast cancer screening.

The interviews provided insight into the influences of the meaning of health and cancer in the women's families of origin and the decision-making related to their current health and views of breast health. This chapter begins with descriptions of participants, followed by answering the research questions associated with each objective. Questions posed to participants were related to their family of origin, their current family, or comparisons between the two.

Demographic descriptors of participants

Table 2 contains demographic descriptions of the participants. The majority of the participants were currently married (60%) or divorced (30%). One of the participants lived for 8 years in a common law marriage and was included in the sample. Five of the participants currently had children living in the home who were between the ages of 11-18. Six of the women had children living in the home that were older than 18 and either in college or serving in the armed forces. One participant lived only with her spouse, and one participant lived alone but had three deceased children. Three participants graduated from high school but did not attend college, three attended college for 2-4 years, one completed a Master's degree, two were in the process of completing Master's degrees, and one participant had a PhD.

Overview of participants

Participants offered a unique viewpoint of the relationship of their family of origin, current family, and comparative look at health and breast cancer. This section includes a brief overview of the women and the family experiences that have shaped their viewpoints.

Table 2

Descriptors of Participants (N=10)

Variable		n	%
Marital Status	Married	6	60
	Single, Divorced	3	30
	Single, Common-law	1	10
Race/ethnicity	White	5	50
	African American	5	50
Household comp.	Children age 11-18	5	50
	Children >18	6	60
	Spouse only	1	10
	Living alone	1	10
Employment	Working Full-time	10	100

	Mean	St. Deviation	Range
Age (yr./mon.)	47.40	3.5	40.25-51.9
Education (yr.)	15.9	3.88	12-24.5

Kim, a 40 year-old African American woman, had been married for nineteen years and had three children aged 11, 15 (sons) and 20 (daughter). Kim's father was a Baptist minister and her parents worked as foster parents (in West Michigan). It was from this foster caregiving experience that Kim was adopted. Within her current family, Kim described herself as an "involved parent", participating in her children's school activities as well as volunteering in church and work events. Kim, self-described as "devoted to her family" and "conscientious" in her employment, felt pulled between the two, leaving little time for herself. However, she was attentive to her personal health care and was the point person for family health in her home. Field notes describe her demeanor as exuberant, cheerful, and willing to share information. She maintained good eye contact throughout the interview, participating because she thinks, "research is a good thing". Kim is employed as an outreach worker at a local health facility, unrelated to cancer prevention and screening. Kim selected her middle name as a pseudonym.

Coffy, a 44-year-old African American woman, was the only participant who had experienced the death of a child. In fact, all of her three children died before the age of three. The death of the children led to the dissolution of her marriage through divorce. Coffy was raised in Chicago, in a primarily African American community and her parents were divorced. Coffy considers her mother and other female relatives as her family, discussing all health-related decisions with them. Field notes describe Coffy as being strong, open, and resilient. Coffy also was the one participant who described the role faith has played in her life, supporting her through the deaths of her children and her recent bout with breast cancer. Coffy was the only participant to have had a personal experience with breast cancer. Because the cancer was found in the earliest stage (in situ), the treatment involved only a lumpectomy. When asked to describe the relationships with those she considers part of her support system she wrote, "As a whole my relationships are good. I can deal with a little stress from time to time in my relationships, but if they become too stressful or conflictual then I cut them off". Coffy, the most educated of the participants, is an assistant professor at a local university. Coffy selected her pseudonym to honor the 1970's sitcom detective who was the first African American female to play such a role.

Sojo, a 47-year-old African American woman, was the mother of one adult daughter. Sojo's parents separated in her childhood, but never divorced. As a result, her father remained integrated in family events and decision-making. While never married officially, Sojo was involved in a common-law marriage that lasted eight years. She described this experience as one identical to married couples in that "we had the house, the dog, the station-wagon…just like the Cleaver's". Loss of employment on the part of her significant other and subsequent drug abuse caused the dissolution of the relationship. However, her ex-partner remained involved in the life of their daughter, attending PTA meetings and participating in decision making in a limited sense. Field notes describe Sojo as being intuitive and insightful, articulate and willing to share her life experience. Sojo described health decision making within her family as being a shared experience, with an extended family that includes brothers, her daughter, cousins, aunts, and uncles. Sojo said that yearly family reunions involve up to seven hundred relatives from around the country. Sojo had vivid memories of the adult women in her life as being strong and powerful in the community (West Michigan). She had four years of a college education and was employed (two full-time jobs) as a receptionist and in the cleaning business. Sojo selected her pseudonym to honor Sojourner Turner, the famous female African American

Rose, a 47-year-old African American, spoke with a gentle demeanor as she responded to the questions. Rose, twice divorced, was the mother of an adult daughter, an adult son and one teenage son. Two of her children had seizure disorders and her oldest daughter had hydrocephalus. Within the past year, this daughter had brain surgery that nearly resulted in her death. However, this daughter was planning to graduate from college in the near future. After the divorce of her parents, Rose's mother remarried and moved the family from Chicago to west Michigan. After that move, Rose remembered feeling lonely, with few friends, a mother who seldom talked with her openly, and missing her friends in Chicago. Rose described the current relationship with her mother as being open and loving, and finds that she shared decision making with her mother and daughter. Field notes describe Rose, as having difficulty discussing her family of origin; saying her childhood was not happy. Rose worked at a local bank for thirteen years and as a result of consolidation and downsizing, became unemployed. After three months of unemployment, she found a position as an administrative assistant in a local health facility. Rose had no formal education beyond the twelfth grade, but was articulate and intelligent. Rose selected her middle name as a pseudonym.

Maya, a 51-year-old African American woman recently remarried after surviving a twenty-year "terrible" marriage, had two adult children and several grandchildren. Maya's parents divorced in her childhood because of her father's drinking. Maya remained close to her father until his death several years ago and was actively involved in caring for her mother who was struggling with cancer. Maya was the only nurse involved in this study and was completing her Master of Science in Nursing. Field notes described Maya as the participant who discussed or focused on memories related to racism and ongoing feelings of racism in her current life experience. She freely shared these feelings and offered insight into how the experiences influenced her decision-making. Maya was the primary health decision-maker in her current family, offering consulting to her adult children and mother. Maya was involved in professional organizations, honor societies and sororities. She was employed at a local health center in community outreach. Maya selected her pseudonym to honor Maya Angelou, the gifted and talented poet.

Bambi, a 46-year-old White woman, had been married for twenty years to her high school sweetheart and was the mother of two adult daughters and one teenage daughter. Bambi lived in the community in which she grew up and recalled her family of origin as one that was not child centered, giving her the impression that she should "be seen but not heard". She described having a good and open relationship with her daughters, discussing topics that were not discussed with her parents in her childhood. She also described having limited conversations with her husband about either of their personal health concerns. Bambi's parents divorced, and her mother recently remarried. Field notes describe Bambi as being lighthearted, willing to share, and insightful. Bambi graduated from high school and worked for an investment firm. Bambi selected her pseudonym because she thought it would be fun and would never again have the chance to be referred to as "Bambi".

Hayley, a 47-year-old White woman had been married for over twenty-two years and had an adult daughter and an adult son, both who attend college. Hayley grew up in West Michigan and worked for her brother in a local establishment. Hayley grew up in a family with older sisters and brothers who "assisted" in parenting her. Hayley described one sister in particular whom she confided her health related concerns. Hayley described herself as a procrastinator related to her personal health needs. She initiated health decisions for her current family but had few personal discussions with her husband related to health. Field notes describe Hayley as responding to questions with brief answers, laughing at some of the questions, and providing limited insight. Hayley attended college for two years after high school but did not complete a degree program. Hayley selected her daughter's name as a pseudonym.

Cissie, a 49-year-old White woman, was twice divorced and the mother of one adult daughter. Cissie grew up in an affluent family in another Midwestern State. She was accustomed to hearing health-related information because her mother was a nurse. Although Cissie's father was deceased, her mother continues to live over three hundred miles away and Cissie was providing distance caregiving to her. Cissie consulted with her mother and daughter for health related decisions and occasionally, with her brother. Cissie was described in field notes as exuberant, insightful, reflective, and expressive. Conversations with Cissie (non-recorded) included topics that she described as Marxist and communist based. It was most interesting to listen to her description of opinions related to the current political culture. Cissie participated in theater and was completing a Master of Art degree at a local university. The pseudonym Cissie selected was a nickname from childhood.

Amy, a 50-year-old White woman had been married over twenty years and had two adult sons (one who attends college) and a daughter in high school. Amy grew up in an eastern state with both parents and moved to this community as a young divorcee with a child. After remarriage, Amy actively participated in schooling events with her children and community volunteering. Amy consults with her mother for health concerns and makes health-related decisions for her children, but not her husband. Field notes described Amy as open, cheerful and genuinely interested in participating in this research, stating she was "honored" to be included in the study. Amy completed high school but never attended college. She described her current full-time employment as an opportunity to get health benefits for her family. Amy selected the name of her daughter for a pseudonym.

Yvonne, a 50-year-old White woman had been married for over ten years to her second husband and had a young daughter from this marriage. Raised in West Michigan, she married young, had one daughter and two sons from that first marriage, and divorced when her children were still in school. Her current husband had one son from a prior marriage, totaling five children in their blended family. Yvonne assisted in health decisions in her family, but viewed this process as interactive with her husband. Yvonne was described in field notes as being artistic and dedicated to her family and church, yet reluctant to respond to questions with reservations noted both verbally and non-verbally. Yvonne graduated with a Master of Art degree from a local university and taught at a community college. Yvonne used her middle name as a pseudonym.

Health behavior overview of participants

These women's narratives demonstrated support for how the early views of health and family discussions related to cancer and breast health have influenced the development of their current view of health related services. Yvonne stated:

> "Well, my mother always was very conscious about uhm.. food and ah.. making sure that we got ah.. just an excellent diet, uhm.. fruits, vegetables, uhm.. that we got enough rest. You know, she-- we were very-- our schedule was very kind of strict and regulated, so we got to bed at a certain time, you know, and uhm.. just things like that. And uhm.. kept the house clean so that things were helping to-- we had a healthy atmosphere to live in."

This passage alone indicates three health related topics (nutrition, cleanliness, and rest) that were the focus of discussions in Yvonne's family of origin. When asked if she knew, growing up, that these activities constituted "health" she stated:

> "No, probably not. That was just the way things were, you know?"

In addition, when asked how she began to think that health was the focus of these activities Yvonne stated:

> "Probably not until I had my own family and started thinking about the best way to raise my family. And then I just kind of followed the same path."

These passages illustrate the influence of the family of origin-learned behaviors or beliefs about health on the views of health within Yvonne's current family. Kim, vividly remembered health related admonitions from her mother stating:

> "Oh, my mother uhm.. she made sure we had our breakfast, lunch and dinner. We always had well-balanced meals. Uhm... she was very clean and she made us very clean. And we had a routine where I mean we knew if we wanted to do weekend activities that our beds had to be stripped and dust bunnies gone and

> things cleaned, things-- all the things picked up. So I- I think that's kind of where I learned some of my health values. I mean wa- wash your hands before you do this, wash your hands before you eat, wash your hands before you cook, wash you fruit before you eat it. It was all instilled in me growing up. Wash, clean, clean, wash."

Kim's family of origin participated in routines that illustrate the importance of certain health related behaviors.

However, when asked about a specific health topic (the meaning of cancer) in the family of origin, both indicated that intuitively, they knew "it" was bad. Kim stated:

> "Ooh, cancer was bad. Uhm... I don't-- I want to say that probably growing up, probably I don't think it-- I don't want to say I don't think it was called cancer. Maybe I wasn't aware that it was cancer, 'cause I don't-- I can't remember if it was like that defined back then. But uhm... it was-- I know it was always something really bad. People were always very, very sick."

Kim's visually stimulating description of cancer illustrated the "badness" of cancer.

Yvonne echoed a similar response to her parents view of cancer, stating:

> "Hmm. I just thought of cancer as something that was growing out of control. And I guess my parents didn't spend a whole lot of time talking. I mean when I was growing up, a lot of issues like that were kind of quiet-- kept quiet."

Yvonne did not describe the perception of cancer within her family of origin in the same intensity of "badness" as

Kim's family did. However, these quotes illustrate how families discussed and dispensed knowledge related to health in an open fashion, modeling learned health behaviors. At the same time, cancer was feared, unnamed, and seldom discussed. As will be shown, these divergent attitudes indicate the great influence of culture in terms of learned behaviors (within the family of origin) on current behaviors related to the use of cancer screening services. Information gained from these interviews also revealed how role relationships, self-confidence, and increased knowledge have contributed to changing views of cancer and the use of breast health services. Ecomaps created by the participants provided visual confirmation of the verbal data. The findings are presented in three sections corresponding to the stated objectives and the supporting research questions.

Summary of Results

Objective One: To explore the influence of beliefs and values about health on the decision to participate in breast cancer screening.

Research Question One: How do women describe their health needs in relation to their family?

The first research question focused on the influence of the family in determining the use of health services. It was assumed that beliefs and values acquired through learned behaviors in the family of origin influence how women view their personal needs in relation to their family. Therefore, responses are categorized according to the family of origin, the current family or comparisons between the two.

Family of origin health beliefs and values

Valuing health and beliefs about what constitutes health are learned behaviors. Within families, individual behavior is influenced by the behavior of others. Children learn from their parents' values and belief systems that are expressed as behaviors. Among the respondents, all valued health. All described activities within their families of origin that were directed toward health. Health values were apparent in the responses to the interview question, "When you were growing up, how did your family define health?" This question was posed to help the researcher understand how women define health in order to then determine how health related decisions were made relative to other family members. Responses among respondents fell into the categories of nutrition, dental care, and cleanliness. It should be noted that none of the respondents verbalized an actual "definition" of health, rather, all provided a description of health related activities learned within their family of origin. Kim and Yvonne spoke of nutrition and cleanliness as quoted in the opening remarks of this chapter. Others indicated the high priority placed on eating a healthy diet. It also is clear that the messengers were either mothers or at times grandmothers, health maintenance is a women's role. Coffy, remembers her mother describing the benefits of eating a low fat diet, stating:

> "- Part of it was because of my grandmother. Now, my- my grandmother's a great cook, and she does a lot of the traditional African American soul food, and stuff. Uhm... But m- mom said that she felt that a lot of it was just really kind of- Some of it was really fattening. Uhm... She didn't necessarily like cooking a lot of those things, or eating them. And then there were some things, because they would eat it so much, she was determined, we're not going to."

In this passage, Coffy's mother recognizes that certain foods or methods of cooking were "fattening", and in the culture of the United States, fattening foods are unhealthy. This passage also illustrates a cause and effect relationship between eating and health that was relayed to Coffy by her mother.

Maya remembered her family having a level of awareness about healthy eating. Her family practiced the eating habits in relationship to visits with physicians and diabetes, requiring diet manipulation to demonstrate that healthy eating rules were being followed. The timing of the healthy eating discussions occurred before these appointments:

> "And when it was discussed it was that my--they were going to visit a doctor for management of their diabetes for my grandmother and my grandfather. So that always meant that-- What I would remember them saying is that they had to do special things prior to their visit. Like, well I can't eat any cake. I can't make any pies. I better not have this. So they would change their eating habits in hopes that it would lower their testing results. You know, their blood sugars or whatever. It was sort of like they were trying to do things differently just before that doctor's visit."
>
> Maya

This quote illustrates that Maya learned the relationship between eating and high blood sugar as health related behaviors and that in her family, all condoned the strategic methods used to achieve an acceptable blood sugar level. While this passage does not specifically identify "health", it does illustrate a cause and effect relationship between a behavior and a disease process understood by family members.

Other respondents received clearer messages about eating as directly related to health. Sojo remembers her mother providing an ongoing and consistent message about the steps necessary to stay healthy, stating:

> "And how to stay alive and well. And so, I can only remember her saying and practicing healthy eating habits and, you know, staying well before you got sick."
>
> Sojo

Sojo clearly learned that healthy eating would result in wellness. This simple passage too, illustrates the cause and effect relationship between healthy eating habits and staying well.

Rose remembered specific foods that her mother identified as providing the necessary components of a diet leading to health. While her mother was not formally educated, her knowledge of nutritious foods was appropriate. Rose stated:

> "Well, my mother made sure that we would eat healthy. She always stressed, eating vegetables. Eat your vegetables was one of the main things that she always talked about, and she always made sure that we would have our green vegetables. She would say, you know, you gotta get your green vegetables. You gotta stay healthy. If you green vegetables you'll stay healthy. So, you know, we made sure that we ate plenty of vegetables."

As stated, Rose learned that eating vegetables would lead to health, illustrating again, a cause and effect relationship.

Two of the respondents intimated that the message related to nutrition and health were supported by both parents, indicating either an overlap in roles within those families or minimally, endorsement of the message on the part of the fathers involved. Amy stated:

> "I don't know, I know my Mom and Dad both were there with me when it happened, and, you know, he'd help her and maybe my eating habits or something, she would say, you know, you'd have to eat better and maybe--or I know, and she'd say "Well you're, you know, more like your father 'cause I don't have that problem but he does have that problem so you must be more like him and you just need to eat more good food, vegetables and things like that".

This statement by Amy was the only response that illustrated a type of relationship between herself and another family member. That is, this statement indicates characteristic Amy inherited from her father but not the relationship between health needs and other family members. Amy also revealed the role that her father played in formulating her view of health.

Of all the respondents, Hayley was the least willing to share her memories. However, nutrition was identified as an indicator of health within her family of origin as well. She stated:

> "Yeah, I just think that, you know, is a good start. You have to be taught how to, you know, how to eat right 'n kinda your parents are an example for you, you know. If they are going to the doctor and taking care of themselves, then I think that reflects onto you."

This statement by Hayley acknowledged the role of the parents as modelers of appropriate behavior.

Bambi described a family of origin that seemed to be the most troubled and the messages less clearly defined.

However, in retrospect, Bambi remembered nutrition as a message and wonders now if it was related to health.

> "I know we did eat well, we weren't allowed to eat a lot o' sugar, we didn't drink a lot o' pop, I don't know if that's because we were a family of four and couldn't afford it, or if it was a health issue, uhm.. I don't think I really, really got conscious about it myself until I was an adult on my "

As in the other messages, the cause and effect relationship between eating and health is evident. However, the message is directed more toward what should not be done rather than what should be done to achieve health.

Among all of the respondents, Cissie described a family of origin that was the most highly educated and included a message directly related to the content relationship of food groups and health. Cissie stated:

> "So maybe those are some of those kinds of things. Eating a balanced diet, kind of one of those things".

In all of these statements, participants indicated that they learned about eating healthy foods within their family of origin and all appeared to be directed toward personal behavior. That is, none of the women indicated that they learned to eat healthy in relationship to the needs of others in their family, but rather, for themselves. Each learned a cause and effect relationship between eating nutritiously and health.

Women also discussed other health topics discussed within their families of origin. As with Kim and Yvonne in the opening remarks, dental health, visits to the dentist or tending to dental care were voiced as descriptors of health among several of the women.

> "We always went to the doctor and uhm.. to the dentist, you know, every six months, and so it was pretty good."
>
> Hayley

This passage illustrated that Hayley learned the importance of seeking dental health within a specific timeframe. Kim even remembered incidents of the dental health message in relationship to caregiving of other children from her parents who provided foster care services.

> "But if the baby happened to fall asleep she had to make sure that we wiped the gums with a clean cloth to get the-- something off the gums, so we'd always do it. We had dental care before we had teeth. I remember that real explicit."
>
> Kim

Kim learned a cause and effect relationship between exposure to formula and dental health.

Maya's memory of dental health was clearly relayed by her mother:

> "My mother did not believe in not having, what am I gonna say, perfect teeth. So, we were-- We did receive cleanings as children. In fact, I never had a cavity until I got into my late 40's. So, I mean…Oh, yeah. She made sure that we brushed our teeth before and after, and maybe that's why-- I mean, she didn't tell us we didn't have candy, but we never, that was

> not anything we did as children, purchase candy or even to follow that. I don't know what we were doing. We weren't eating candy though…So I do remember dental being a priority. We brushed our teeth before or when we got up, and she made sure that we brushed our teeth after meals. She made sure that we brushed our teeth before going to bed. That was very important to her to have good teeth.
>
> Maya

Maya learned the relationship between eating sweets and dental health in terms of the development of cavities after exposure to sweets.

Rose also remembers her mother's concern for her teeth and the message that eating candy could lead to cavities.

> "And so she didn't want us to eat a lot of sweets. That was one of the major things. And I think also, you know, she thought about us having cavities because she was really concerned about our teeth, you know. She didn't want those to go bad. But, it was mainly, you know, one that was one of the things that she said no."

Rose learned the relationship between sweets and the development of cavities as part of dental health.

Women also described health messages related to environmental concerns. Cleanliness as a health related activity was recalled by a number of the respondents that was related to personal hygiene, stating:

> "I think just cleanliness, uhm.. you know, making sure you shower, wash your hair. That is a good thing for you to learn when you're younger, and I mean you just want to be clean."
>
> Hayley

Hayley learned the importance of cleanliness as an indicator of health and described how her siblings teased her if her hair was dirty.

The impression of hand washing hit home with Kim and Cissie who stated:

> "She would just say that, you know, "It's so easy. Your hands are such a dirty place 'cause everything is dirty. You don't know who touched anything last and you need to wash to your hands because you use your hands and you stick 'em up in your eyes and you'll get something."
>
> Kim

This passage illustrates an example of Kim's mother's awareness of the transmission of infection and that Kim learned the importance of hand washing to avoid the spread of "bugs".

Cissie laughed when remembering the hand-washing message that was directly related, by her mother, to health.

> "Well, she was a rabid hand washer, I mean, you know that it was obsessive/compulsive or anything, but she, you know, she did- She instilled that in me, to wash your hands frequently, to stay healthy. What else? I think I've grown up with a real positive sense of what health is, even if it's not necessarily verbalized."
>
> Cissie

Cissie learned the relationship between hand washing and health, and acknowledged that the behavior was learned through observation and messages.

Yvonne viewed cleanliness, as an environmental requirement within the home, stating:

> "And uhm... kept the house clean so that things were helping to-- we had a healthy atmosphere to live in."

Yvonne learned the importance of living within a clean space as a method to achieve health.

Finally, two of the respondents related dressing warmly as a health message relayed within their family of origin.

> "I don't really remember it necessarily being, you know, like a- a big- a really big issue, probably because of the fact that c-colds were like common. But it would be the thing, "Okay, dress warm, do this. Do that."
>
> Coffy

Coffy learned indirectly that dressing in certain ways could lead to avoidance of an illness.

Among the varied types of health behaviors shared within Cissie's family of origin, Cissie stated:

> "...And, also dressing warmly. Maybe that's to stay healthy, too. Dressing warmly for the weather. So maybe those are some of those kinds of things."
>
> Cissie

In retrospect, Cissie expressed the learned behavior of the importance of dressing warmly to avoid illness.

The themes described by the respondents illustrate the types of messages within the family of origin that helped to shape their beliefs and value of health. These messages related to attention to personal hygiene, nutrition, dental care, and appropriate dress are examples of health beliefs. None of the messages described the relationship of these personal health activities to the general well being of the family. For example, none of the women described the importance of preventing the occurrence of a cold, or cavities because of the expense for the family in treating the disorder or to prevent the exposure of the rest of the family to the disorder. Few explanations were given regarding the rational and reasoning for the behaviors.

Family of origin health memory

Respondents also were asked the question, "What is your first health related memory?" This question was directed toward understanding whether women learned to think about the relationship between health and others within the family. While respondents described (defined) health within their homes as staying healthy through eating properly, cleanliness, dressing properly, and activities like receiving dental care, most recounted their first health related memories as unpleasant.

Kim precisely directed healthy behaviors. Kim recalls her first health memory associated with childhood immunizations.

> "I'm gonna say shots. Uhm... I just-- I think getting ready for school and making sure that we were-- that our immunizations were up and going and having that physical done right before I think probably kindergarten or preschool. Yeah."
>
> Kim

Kim learned that health was related to immunizations and having a physical examination in relationship to school attendance.

Maya remembered growing up in a home that encouraged her participation in extra curricular activities such as playing the violin and ice-skating. Her first health related memory was as a result of an accident incurred during an ice-skating outing. Maya recalled:

> "Oh, I guess the memory that I can bring to place was that I fell on the ice. And I started to bleed and my brother's carried me home and I had to go to the emergency room to get stitches."

Maya learned that receiving an injury would lead to the rendering of a health service.

Hayley also remembered her first health memory associated with an injury. The unpleasantness of the injury was magnified for Hayley by the fact that she was away from home and a doctor that she loved and trusted. Hayley stated:

> "Well, it was when I got bit by a dog…I… uhm... It bit me in the nose, and my whole side of my nose came off. And I remember goin' into surgery and to the doctor, and I was kickin'and screamin', and all I can remember sayin' is I wanted my Dr. Wilcox that I went to. We were in Albuquerque, and I went to Dr. Wilcox in ____________, and uhm.. I-I can just remember kickin' and fightin' in that room with the nurses and doctors, and they sewed my face up and I had to wear a mask for quite a while and just doctoring that. And I remember wearin' a Band-aid for months over my nose."

Hayley learned that an injury lead to an unpleasant health related experience and she learned that injuries precede health-seeking behavior.

Sojo remembered that she went to her grandmother's house for lunch during the school year. Usually viewed as a pleasant time with her grandmother, Sojo recalled her first health memory in relation to one of these noontime encounters. She stated:

> "I went to my grandmother's house every day for lunch and I was in about the fifth grade and I went to her house that day and I couldn't get in, and like I said I'm always curious, you know…And, I'm looking through all of those windows and I see her and she's laid out on the floor. I bust open the window and I go in there and, you know, she's unconscious."

Sojo vividly learned that an illness could have a negative outcome for her family.

Rose's her first health memory was associated with her sister's health experiences rather than her own. Rose was raised in a family in which she felt distant from her mother because her mother had remarried and moved the family from Chicago to western Michigan. As a result, Rose grew close to her sister. When her sister encountered the health care system, the episode made a distinct impression on Rose who stated:

> "The very first thing I remember is my sister. She had scoliosis. And they had to do that back surgery on her, and when I went, you know, we went to visit, my

> mother and I, I passed out. And because I saw this blood and I never seen, you know, blood like that, and it was just too much. And I think at that point that's when I said, "You know what, I don't think I need to be in the hospital or the doctor's office anymore, you know, because of that."

Rose experienced the unpleasantness associated with health care and chose to avoid experiences similar to her sister's.

Yvonne, too, recalls her first health memory associated with a sibling. She stated:

> "I guess the only thing that comes to mind is- is an injury that my brother had…Well, we were outside playing the snow and we were knocking icicles off the roof. And he happened to have <laughs> a- an icicle land on his head. And we rushed to the hospital and uhm... took care of it."

Yvonne learned a cause and effect relationship an injury and entry into the health care system.

Three respondents recalled events associated with illness and uncomfortable feelings related to procedural tasks.

> "Oh I know what that is <laughs>, this is not very pleasant but I-I had a problem when I was little, going to the bathroom, I was always constipated and my first health memory is my Mom giving me an enema, those old terrible enemas, that's my first-"
>
> Amy

Amy perceived the enema as an unpleasant health experience.

Bambi also recalled a memory of a health related procedure, stating:

> "I can remember going to the doctor and having, you know, the temperature in your butt. Uhm... the big traumatic uh... I had my tonsils out, I can remember that, you know, being in the hospital with that little emesis basin, and-"
>
> Bambi

This passage illustrates the association of medical paraphernalia with an unpleasant health memory for Bambi. Cissie recalled having a disease and as a result of this disease her parents implemented certain strategies.

> "I think that the earliest thing about health related events, I think I must've had measles. And I must've been under five, probably under four years old, 'cause I was in a different bedroom than I was later on. Remember being in that bedroom. Remember being told I have to stay there. And I remember my parents going off, not that I was left alone."
>
> Cissie

Cissie learned that having this type of illness left her feeling isolated in some way.

These memories illustrate the unpleasantness experienced by the respondents either through an actual illness or through injury. Consequently, each respondent began to learn the relationship between the event and entry into the health care system. Many of the women remembered the relationship between the experiences and other family members and the dependence of family members on each other for assistance.

Family of origin adages and sayings

The use of language in terms of sayings and adages was examined to discern the delivery of health messages within the family of origin. Participants were asked, "What kinds of sayings or adages do you remember your parents or grandparents using to talk about health?" Most of the respondents found it difficult to cite a saying or adage used in their families to impart health messages. What came to mind for most were health related, as in the example by Kim who stated:

> "Consumption sticks out in mind. You're-- some of you-- when you get the consumption that was gonna be really bad."

Kim learned that a particular illness named "consumption" was to be feared.

Maya remembered fear as an associated feeling when discussing sayings and adages used in her family.

> "Well, I don't know if it was a fear factor. I mean, I guess for me, all I can remember is from that experience and from childhood, it was a fear factor that was introduce. I needed to do this because if I didn't, then something would be bad happened to me. I mean, I either had to follow directions or I had to be submissive. I had to be something in order to not have these bad things happen. So I guess, it was more of a negative response…" Maya

Maya's recollection of a saying or adage used to relay health information demonstrated a subtle cause and effect relationship between a particular action and something bad happening.

Sojo recalled a commonly used saying about "An apple a day keeps the doctor away" and recalled other references to sayings but could not recite them during the interview.

> "The apple a day, and there was something about the gout. I don't I can't ever remember that one. I work with people that, you know, deal with health issues and I always try to remember the saying about the gout. I don't know. I can't remember it."
>
> Sojo

While Sojo could not remember the particulars of the message, she learned that sayings or adages could be used to impart health information.

Coffy, who remembered her mother's reference to dressing warmly, shared a comical response:

> "Oh, God! Oh, my mother was good for saying, "They bury 'em cute."

When asked what that meant to her, Coffy stated she did not know, but that even now she recalls that saying on cold and wintry days. Therefore, Coffy learned through the use of a saying the importance of dressing warmly.

Other respondents conveyed vague recollections of health-related sayings or adages used in their families of origin. Amy's memory focused on the value of health when she said:

> "You got your health, you got everything <laughs>."

Amy learned the value of health as a priority in this simple example.

Hayley's memory focused on an action in response to an illness that was viewed as health related behavior:

> "Boy. Just if uhm... I don't really remember anything like as a word, but I just if you were sick, you were supposed to go to the doctor. You know…"

This passage indicated that Hayley learned about health seeking behaviors in times of illness.

Cissie's focus referred to her mother's emphasis on hand washing that imparted a level of awareness about healthy behaviors.

> "She instilled that in me, to wash your hands frequently, to stay healthy. What else? I think I've grown up with a real positive sense of what health is, even if it's not necessarily verbalized."

Cissie learned through clear messages used by her family of origin to impart healthy behaviors.

Bambi referenced a saying, unrelated to health, but acknowledged the lack of communication that occurred in her family.

> "I wanna say "Don't cry over spilt milk", but that might not have been about health, but, you know, you're not s'posed to get upset, remember "Don't cry over spilt milk". <Laughs> I can't think of any, just that one. We must not have talked much <laughs>."

Bambi learned through adages or sayings the inappropriateness of certain behaviors within her family of origin.

The use of health related adages among the other two respondents' families were either not evident, or were non-existent.

> "Oh, my. Well there are a lot of family sayings, but I'm trying to think of some that are related to health."
>
> Yvonne

> "There weren't any. There just weren't any that I can recall."
>
> Rose

These passages illustrate that for Yvonne and Rose the use of sayings or adages were not remembered as significant within their individual family of origin. Several of the African American women recalled specific home remedies rather than sayings and adages.

Kim's memory focused on home remedies used across the generations in her family. Kim stated:

> "Uhm... my mother always had older- older friends and they always had their little home remedies and old wives' tales. And so I remember a lot of-- I can remember a lot of that…Oh, yeah. If we got a cold, then we got uhm... we got these hot toddies with the lemon and the- the lemon and the whisky and the uhm... I think they put some-- even some onions in it and made tea. And they brewed it up really strong. And <laughs> you could have-- you could have a hot toddy going on. And uhm... I can remember uhm... I don't know what the dandelion wine was for, but there was

> this- this lady that lived up north in one of our little houses and uhm... she would make this dandelion wine and pretty much used uhm... all kind of these tree type things. Uhm... when you got the mumps she got the sardines around your neck or this stinky stuff something around your neck to kind of help the swelling. Uhm... earaches got a cotton ball with sweet oil in your ear. <Laughs>. I kind of grew up with all those kind of…"

Kim's family used a variety of methods to ensure health.

Coffy remembered distinctly a home remedy that as an adult she looked for ("Three Sixes") but was unable to find. Coffy stated:

> "First of it, was the praying. Uhm... If you had a cold, the honey and the red onion. Honey, red onion and was there something else with it? I used to just think, "Oh! This is so gross." "Three Sixes", oh God, I remember! We used to have to do- take "Three Sixes", with quinine."

Coffy could not recall what "Three Sixes" was, but remembered the distinct taste. Coffy also recalled the use of faith and prayer.

Maya remembered the use of home remedies stating:

> Well, I guess I have to go back to home remedies. I mean, they would do the toddy's. They would do some of the folklores. Like toddy's is the honey, the lemon. Sometimes they would put a little dash of alcohol to give you this big, you know, kick. <laughs?"

This passage illustrated a specific internally consumed remedy. Maya's family also used other types of home remedies. Maya recalls:

> "Oh, yeah. I mean, home remedies even goes back to massage. We would massage my grandmother's feet. We would massage her back. I mean, she taught us early how to do those kinds of things because it made her feet feel better. And when I think about it, that was a very loving relationship. Maybe that's why we all were very drawn to my grandmother because we always touched and did things like that for her."

This passage also illustrates the use of a complementary therapy and the value of touch.

Rose was unable to remember specifics, but recalled that her family used home remedies. Rose stated:

> "…But, I remember, even my great aunt, they did not believe in going to doctors. They had what they called those I can't think of it right now. But they just had their own home remedies."

The passages presented illustrate the foundation for health beliefs and behaviors learned within the respondents' family of origin and how these women learned about their health needs in relation to their families. While not receiving a clear rationale of the need for the individual to stay healthy within the home, they each learned strategies to maintain personal health. The next questions explored how women learned about cancer within the family of origin understood their personal screening needs in relation to their family.

Family of origin and cancer meaning

The next questions asked the respondents to recall the meaning of cancer within their family of origin and to describe their first memory of cancer within their family of origin. Because the responses to these questions overlapped, they are presented together.

In the opening remarks Kim described the negative meaning of cancer within her family of origin. Other respondents recounted similar experiences. Coffy remembered her first encounter with cancer in association with a college friend:

> "It [cancer] really didn't have a meaning. I mean, I- I had heard of it, but I wasn't knowledgeable of anybody having it. Uhm... First person I can remember having cancer was uh... my uh... my best friend in high school, her mother. And we were in college and I went to go visit her, because it was my spring break. And I- I went to go visit her…And we were gonna' go to a party, and something had happened, and we were taking our time getting out the room, and her mom called. And her mom told she had can- that had been diagnosed with cancer."

This passage illustrated a family relationship within the context of the cancer diagnosis. Coffy remembered how unpleasant the experience was for her friend.

Three of the respondents shared death as a common memory associated with cancer; hence the meaning of cancer for these respondents became death.

> "Well, it was death, certainly. And my first experience with cancer would have been my mother's mother. So it would be my maternal grandmother. She died of cancer."
>
> Maya

This passage illustrates Maya's first memory of cancer in association to her grandmother's death.

Sojo recalled a relative with cancer who died:

> "That was just as a matter of fact I had an uncle and he had some kind of stomach cancer and he was just dying and he just literally he was the baby brother and he ended up with the bag, you know."
>
> Sojo

Sojo recalled the memory of her uncle with cancer and particulars related to the disease (the "bag") and the relationship between cancer and death.

The memory Bambi recalled also demonstrated a family relationship:

> "The only issue when I was small that I remember was my great-grandma died of cancer and I remember my mother and my grandmother talking about my grandmother taking care of Great-grandma Hansen, when she got very sick and she died o' cancer."
>
> Bambi

While this passage illustrated a family relationship to cancer, there is no indication that there were other family members concerned with their personal health needs.

Hayley's memory of cancer indicates awareness for personal needs:

> "Just, you know, that uhm... they could-they could die from it. They may not be around, and you need to if you think anything's wrong, I guess you just you need to go get it checked out."
>
> Hayley

Hayley learned about appropriate health seeking behaviors because of others' experiences with cancer and death. Others referenced cancer associated with fear. While not specifically stated, the meaning of cancer for these women was fear. This was expressed in the tone of their voice and non-verbal actions when discussing these questions. Rose's eyes grew wide when she recounted:

> "The only thing that I can remember that cancer was something you didn't want to get."

While Rose learned that she never wanted to "get" cancer, there is no indication of an awareness of her personal health needs in relation to her family.

Amy described her parents' sense of frustration, which she interpreted as:

> "Just something very bad that they didn't know why it happened and that uhm... I do remember them talking about uhm... all the money spent on research and why couldn't they figure something out."

Amy learned that cancer was "bad", but did not indicate a sense of learning anything about her personal health needs in relation to the family.

Yvonne also indicated that in her family, the topic of cancer was a non-topic of discussion. As a result, her understanding of the meaning of cancer was limited, but closer to a description of actual cancer cell activity.

> "Hmm. I just thought of cancer as something that was growing out of control. And I guess my parents didn't spend a whole lot of time talking. I mean when I was growing up, a lot of issues like that were kind of quiet-- kept quiet."
>
> Yvonne

Yvonne indicated learning two things in this passage. One, that cancer was uncontrollable, and two, that cancer was not an appropriate topic of discussion in her family of origin.

Cissie's response evoked the academic manner in which her family discussed difficult topics. This open and honest, matter-of-fact pattern of discussion seemed to help Cissie understand cancer in terms of cause and effect and death and dying. That is, Cissie began to understand that participation in certain behaviors could lead to cancer and result in death. She recounted the practicality of her mother's discussions:

> "That's very interesting. I don't know when that came about in terms of the family consciousness. Somebody must've had- I'm sure some neighbors had cancer. One thing that I think having a nurse for a mother, but also growing up at the time that we did, we had an awakening to these ideas of cancer, or disease, or even death and dying that was happening, because you know, like Elizabeth Kubler Ross was coming out and

> looking at death and dying that hadn't been done before in this society. And so, we were kind of going along with those things. My mother's always been very, very, practical about terminal illness, or big things like that."

Cissie learned the relationship between cancer and death, but did not indicate gaining an understanding of personal health needs related to the family.

Family of origin cancer sayings and adages

The question about sayings and adages for health used in the family set the stage for the question, "What kinds of sayings or adages do you remember your parents or grandparents using to talk about cancer?" This question was asked to understand how women learned about their cancer related personal needs and what specifics they learned through the use of sayings and adages. The responses to this question reflected the lack of understanding of cancer; the associated fear felt because of this lack of knowledge and the media attention toward cancer in the 1960's. John Wayne referred to cancer as "the Big C", rather than using the actual word. That message was remembered by two of the women.

> "I think nope, just they didn't say anything about I know I have heard the Big C."
>
> Sojo

This passage indicated that Sojo learned very little about cancer within her family of origin.

Cissie recalled a similar memory:

> "Whether it was- If we start- I think when we were growing up, you're the same age as I am, we started to see anti-smoking ads, and I remember vividly, John Wayne doing anti-smoking ads. And I remember that that was- I understood that he couldn't even say cancer. He said, "The Big C." And he was talking about the fact that he had been a smoker, and now he's got lung cancer. But, I remember he couldn't even say cancer. The Big C."

Perhaps because Cissie's mother talked more openly about cancer, her understanding that Mr. Wayne could not say the word "cancer" was significant. She does not indicate an understanding of personal health needs relative to the family at the time of this memory.

As shown, the question provoked vivid memories for some, memories of a child visualizing cancer and the way that cancer affected the individual. These thoughts begin to demonstrate the development of fear associated with cancer. Kim stated:

> "For some reason in my mind, I always thought that cancer was kind of like this sore kind of thing… It wasn't something that you could see. But I- I think that's kind of my first memories of like what cancer was. I mean you heard it was just something really gross like a big ooping sore or something."

Kim came to think of cancer with a sense of "grossness" but not with a sense of personal fear.

Though not described as a vivid memory, cancer was associated with death at an early age by Maya who stated:

> "Well, when it was referenced, it was always like, well, you know, mama had cancer until, you know, ultimately she was gonna die or she did die. Or she died from cancer. So it was always referenced to death. There was, you know-- There wasn't that period of treatment. There was no period of prevention. I mean, it was just always associated with the death-- What I want to say, a definite sense you were gonna die."

This passage by Maya indicates awareness that there was not a clear message about prevention and personal health needs related to cancer.

Others also spoke of fear and death associated with cancer, but acknowledged that cancer was not an appropriate topic of conversation within their family of origin, and hence the failure to associate sayings or adages with cancer.

> "Cancer was really not a discussion in the family other than, you know, that's something, you know, if you get it's gonna be tough. You know, you're gonna die from it, and that's pretty much it. There was no detailed information. There was no we were gonna look this up and see what the cause is. There was none of that."
>
> Rose

Rose indicated that she learned that cancer was an inappropriate topic of conversation in her family of origin, and thus she learned little about her personal health needs.

Bambi's family experience was similar:

> No I-I know the one, I remember when I was home and I was a teenager, the area, I remember my Dad talking about people __________, that they thought that was uh... there was a lot of people up there that had

> cancer and that that-he thought it was related because all the factories are up there. But other than, you know, like family related or illness issues we didn't really discuss anything like that."
>
> Bambi

Bambi acknowledged that she did not learn about her personal health needs related to the family.

These passages describe what women learned within their families of origin related to health, healthy behaviors, and cancer. Most of the learning focused on individual behavior. Few references were made to the personal needs of the individual in relationship to the rest of the family. To understand how respondents adapted some of these learned behaviors to their current family, they were asked "What sayings or adages do you use in your current family related to health?" The responses reflect health messages learned in their family of origin.

Current family sayings and adages

Kim used media depictions of "health" to illustrate healthy behaviors to her family. Kim stated:

> "Oh, yeah. Uhm... well I use the milk thing all the-- I'll use the milk thing all the time. And I usually just say, "I need to see those milk mustaches," and they just kind of laugh. And uhm... 'cause I say, "You're strong-- you're strong big boys. I need to see that milk mustache." And then my daughter says, "I hate milk." <Laughs>. Yeah, uhm... fruit-- I always tell 'em that they- they got to eat fruit. And vitamin C. I- I push that. I push-- I push vitamins. Uhm... and a lot of stuff you just say because you

> hear it. You hear it on TV and I think you just kind of-- you just pick it up and you just kind of incorporate it in- in your living. And I think they do a pretty good job throwing it back at me too."

Whether consciously or unconsciously, Kim had incorporated appropriate media messages and used them to reinforce appropriate health behaviors.

Sojo also based her messages on those promoted through print media. Sojo stated:

> "I don't think I use an adage. I will say, "Make sure you're drinking eight glasses of water a day. Your body's comprised of water mostly. You need to have that in there." "I don't like water." "Well, it doesn't matter if you don't like it, that's what you need, you know?" Or smoking or alcohol. I don't think I have adages. I don't have adages. I have whatever I pulled off the pamphlet that we're trying to teach the patients that I deal with."

Sojo used information from pamphlets to reinforce relevant health messages.

Amy's messaging reflected her focus on the provider as the expert in health matters. Amy stated in her use of health related adages or sayings:

> "No I really don't, I mean it's basically like it was in my household, as long as they're okay I don't, you know, but as soon as they're-something's wrong, "We're going to the doctor right now, 'cause we're gonna get it checked out". So I don't really like-"

Amy's message was less focused on prevention than those imparted by the other respondents, and more focused on reactionary uses of health care.

Bambi also focused on known information to achieve health in the messages shared with her family. Bambi stated:

> "Well I don't know so much that I use sayings and adages, I-I know I-I do talk about, you know, drinking your milk, and, you know, having healthy bones and eating your vegetables and, you know, same thing, we don't have cookies, you know, we've got apples or oranges, uhm... if we do have snacks, I'm a grandma, you gotta have something, but we buy the fruit, you know, the fruit snacks…"

This passage illustrated the use of direct messaging rather than indirect referencing to impart health information. Cissie does not use adages or sayings, although she recalls familiar sayings:

> "None that I can think of. You know, that old apple a day keeps coming back into my head, and maybe that's something that, you know, I do believe, not that I practice what I preach, but I do believe that if you eat right then you will-- your body can function much better."
>
> Cissie

This passage too, illustrated attention to nutrition. Finally, Yvonne messaged appropriate health behavior reminiscent of that heard in her family of origin. Yvonne stated:

> "Oh, uhm... I say things like, "You really need your rest. Your rest is more important that this ten o'clock TV show." <Laughs>. You know?"

The responses to questions used to answer Research Question One, "How do women describe their health needs in relationship to their family" provide a sense of how women describe their health needs in relation to their family. Within the family of origin, these women learned the behaviors that their parents believed were health related (nutrition, rest, cleanliness, and dental health). Some of these behaviors were transmitted to their current family (nutrition and rest). Cancer within the family of origin was not discussed in an open fashion. A belief about personal responsibility to maintain health was clearly evident as women described an understanding of causal relationships between behaviors and health learned in their families of origin. The women seldom described their personal health needs in relation to their family. For example, none of the women stated that they needed to stay healthy to take care of their family, to maintain employment or to see their children grow. However, women did describe beliefs that within the family each member should participate in certain activities to maintain health. This idea relates to personal responsibility, agency, and autonomy.

These responses to Research Question One formed a background with implications for understanding how women learned about breast cancer as a part of health.

Objective One

Research Question Two: "Where do women learn about their breast health needs?"

The second research question was designed to explore where women learn about their breast health needs and to determine if they learn about these needs within their families of origin or as adults, from health care providers. Respondents were asked the question, "What did your mother or other family member teach you about breast cancer, in particular, or breast health?"

Breast health

Many of the respondents laughed when answering this question, recalling the lack of information shared between mothers and daughters, either related to breast health or breast cancer. Some remember receiving advice about their breasts related to a sexual nature, but none recalled their mothers teaching them about breast health or breast cancer.

Sojo recalled her mother sharing advice about how to "manage" her body in terms of relationships with boys. Sojo stated:

> "Nothing. Nothing. There wasn't any discussion about checking them. You were discussed who not to touch them."

This passage illustrates Sojo's non-recollection of breast health related information.

Cissie found the question humorous, particularly because of her mother's Southern Baptist background. While her mother was a registered nurse, and was able to discuss health-related topics in an academic sense, she was unable to discuss the breast, because of its sexual connotation.

> "No. Breast health- was there some thought of breast health in our teens? Did you have some? I don't think there was any thought of any kind of breast health in our teens. No, that's not what any teenager, I ever heard of ever thought about breasts in terms of health…Breast health. No, and no, because she was also a very uptight Southern Baptist, RN…But I did think it was real ironic that she was- There was this prudishness through- from her, that you know, we just didn't discuss anything sexual, so breasts beyond- Breasts were a little too sexual to talk about, even in terms of health. And I, you know, even any female health stuff, I don't remember any kind of message coming from my mother the nurse! Who would have all the information about that, so, whatever stuff we got about female health came from school."
>
> Cissie

Even though her mother was a nurse, female health information was relegated to the school systems.

Rose, who was reluctant to share much about her childhood because of unpleasant memories, did acknowledge that she learned very little from her mother, and that there were topics that were considered off limits.

> "I don't even think we could even say the word breast in front of her, you know, without feeling like, you know there was gonna be trouble behind it. So, you know, to talk about those things, you know like personal parts of the body, especially on women, we could not discuss that."
>
> Rose

This passage illustrated Rose's clear understanding of appropriate topics for discussion. In her family of origin there were few opportunities for health discussion. This theme continued with other respondents. As stated by Coffy:

> "Nothing <laughs>, nothing, it was-it-it wasn't an issue, cancer in any form or fashion…Uh-uh, uhm... I uh... learned it-I guess I got something about checking myself from the-basically from the doctor when I went to uh... it-it's-it just really wasn't a big issue, you know, it was kinda like "Oh did you examine your breasts?" okay and then he'd do it, but I was an adult uhm..."
>
> Coffy

This passage illustrated that as a youth, Coffy learned nothing from her mother about her breast health needs. Maya expressed a similar experience:

> "Well, when I was younger, we didn't even talk about female parts <laughs> like a breast. There was no..."
>
> Maya

As described by Maya, Sojo succinctly described the content of breast health discussions when she stated:

> "Nothing."
>
> Sojo

Amy recalled similarly hearing about breast health as an adult rather than in her youth, stating:

> "I don't think my Mom did, talked to me about it. I think when I was in my twenties, I think she mentioned something about well women of that age don't normally get breast cancer and uhm…"
>
> Amy

The message from Amy's mother indicated a connection to breast screening when she stated, "women of that age don't normally get breast cancer".

Yvonne's experience was similar, learning about breast health as an adult and not from her mother:

> "I was nineteen. And uhm… And I remember now, uhm… my mother didn't teach me anything about it, but I remember her being really sad about the fact this was a friend of hers that- that was dying of breast cancer. And uhm… but I don't remember anything like, you know, conversations related to teaching me about it. I just uhm… remember her talking about how, you know, what a sad thing it was."
>
> Yvonne

Yvonne remembered her mother's sadness associated with the diagnosis of cancer for the friend rather than a message specific to breast health. Bambi recalled a procedure that her mother experienced, stating:

> "Again I can remember my mother having to have a biopsy, and that's it…"
>
> Bambi

While Bambi recalled the procedure, the message did not include any breast health related information shared with her by her mother.

Kim remembered vividly, her mother imparting wisdom related to breast health (self-exam) and Kim's reluctance to follow her mothers' advice. The reluctance stemmed from the perception of the self-exam as fondling oneself.

> "Hmm. Well she did…she always said about checking… "Are you doing your-- are you doing your self-exams?"

> And it would be like, "No, I'm not touching myself." And she'd say, "No, you really need-- you really need to just uhm... you really need to just feel around there for lumps and bumps and stuff…
>
> Kim

This message relayed an association of the breast with sexuality. Kim expressed discomfort with examining herself that persists today.

Hayley, too, recalled her mothers' advice to participate in a breast self-exam as a form of breast health, stating:

> "Uh… Mostly probably how to give yourself uh… like a self-exam…Uh… my mom aft-like after I went to the doctor and, you know, she'd just remind me, "You need to do that," 'n so I can just remember that's one of my memories."

Current family and breast cancer screening

Respondents were asked the question "Tell me what you know about breast cancer screening" to understand their current knowledge related to their breast health needs. Most understood their needs, and some specifically identified who or how they learned this information. Kim stated:

> "Well, the self exams, because you can feel things, because they're yours and you should be feeling and you should be feeling on 'em and knowing what feels normal and what's-- so really the first screening really should start with you, because if you can detect something, no matter how minute you think it is, and then call up and get a follow through, I think you are able to catch stuff sooner than if you don't pay any attention to it, and things are going on, and you're not totally in tune with what's going on with your body. So I think it's-- I think it's very important that- that you do it. Because even though

> it's not nice and you don't really want to do it, it's almost a-- it's almost a nec-- a necessary thing, because the one time a year that you go in to see your doctor, you know, if, you know, they might not even-- they might not even feel it, because they do it all the time, and they don't know-- they don't know the texture of your breasts, if-- as if you were palpating it all the time I guess."

This passage includes a reference to beliefs learned in her family of origin when Kim stated, "…even though it's not nice…" to describe a self-breast examination.

Coffy's response references her current interaction with the health care system as a result of her personal diagnosis of breast cancer stating:

> "They told me they'd see me this spring when I come in for my annual again.'
>
> Coffy

Coffy's response was specific to her post surgical needs for breast cancer screening in the immediate future rather than ongoing screening.

Maya, a nurse, was more specific related to her needs, stating:

> "Well, screening means that you're going to go and do your recommended mammography. And that means that you have reached a certain age and you are following the standard guidelines."

This passage illustrates an awareness of the use of standardized guidelines to direct the needs that are age based.

Sojo describes a similar, yet less specific acknowledgement of age based need for "it" (mammography), stating:

> "I don't know what I know. I try to go and get it done once a year now since I've been 40."

Rose acknowledges her mother's influence related to the use of screening services that are also age-based.

> "Well, to me, because my mother is trying to get me signed up seems like every year-- go and get a mammogram, go get a mammogram-- and I think she's like, well, after 45, or... There was an age she threw out at me. After 45, I just went and got my mammogram every year. I said, okay, fine. So now I tell you, she's gung ho. If you ever wanna see someone-- and I'm really, you know, amazed at that, you know. And I'm really amazed that she even talks about breast cancer to me. Because we could not talk about those things."

This passage illustrates a change in the relationship between Rose and her mother that is welcomed.

Amy describes an aged-based awareness of screening needs and the activities she participates in to screen appropriately. Amy stated:

> "Well, I know that uhm... I do self-exams, and at the age of forty I think you go for your mammogram. And that's what I know. <Laughs>."

Hayley was uncomfortable in sharing her knowledge, stating:

> "Oh geez, I guess I just uhm.. I've, you know, read it before. I've kinda seen a chart 'n, oh, we get a pamphlet in the mail from our uhm... insurance company—'

Whether the discomfort was related to the topic or lack of knowledge about screening is unclear, but Hayley did acknowledge how and where she learned about cancer screening.

Cissie described a disconnect between her knowledge and actual practice stating:

> "Well, I mean I know about self exam, doing self exam. And of course-- and I'm a good medical consumer and I rarely do self-exam, but I do it. You know, I pay attention to things and, you know, every so often, but I'm just not a real regular person, so I have to say, you know, yeah, I don't do regular self-exams. But every so often I do regular self ex-- no every so often I do self-exams. So, I know that…But I poke around there and look for lumps and all that kind of thing. And I get regular mammograms. Now that I have insurance I get regular mammograms."

Cissie's honest account of her actual practice versus what should be done may be indicative of other women.

Yvonne stated accurate knowledge and the influence of this knowledge on her daughters' behavior. Yvonne stated:

> "Uhm... I just know that personally I need to have a mammogram, uhm... and I usually do that once a year. And uhm... breast self-checks once a month. Uhm... my daughter had a lump and uhm.. we talked extensively about, you know, how she discovered it and all of that. And uhm... she did have it removed and it was not cancerous. So uhm... so we just talk about how important it is to, you know, to take care of yourself as far as having screenings."

This passage illustrates the belief of personal responsibility and breast cancer screening.

These accounts of health behaviors and memories, cancer and cancer memories set the stage for exploring the second research objective.

In response to Research Question Two, these memories illustrate that few of the women learned anything about breast health from their mothers. As indicated by some, breast health was thought of in terms of sexuality rather than in relationship to cancer. By not learning about their breast health needs in their family of origin, they became dependent upon breast health knowledge acquired as adults. A theme related to personal responsibility is evoked from the responses in terms of health and breast cancer screening. Beliefs and values learned within the family of origin have been transformed within the current family to impart the same messages to the family members. As part of that learned behavior, personal responsibility for health and age appropriate screening is apparent.

Objective Two: To explore the influence of life course transitions/events on participation in breast cancer screening.

Research Question Three: "What are the effects of life course transitions and events experienced by women on their participation in breast cancer screening?"

This question was explored by first examining the responses related to the life course experiences of the respondents and then exploring responses to questions about breast cancer screening participation.

Life Course

Many of the memories described by the respondents follow a life course perspective. That is, most families only enter the health care system during times of illness or injury and during well-child visits. As families make the transition to having children access to health care focuses on care for the children. Within their families of origin, several of the respondents recalled home visits from doctors and their mothers visiting doctors for their own personal care. While during times of stress mothers may seek health care for their children and not themselves (Campbell, 2000), the respondents did not voice an awareness that their mothers were sacrificing in this way. Other memories described events such as death and divorce or experiences related to moving out of the family home. The following section will be presented in relationship to historical influences followed by specific events.

Life course and historical influences

From a life course perspective, historical time and the influence of political beliefs influence the experience of individuals and their families (Price, et al., 2000). For African Americans, health care has been plagued with access issues and mistrust. This is illustrated by the African American respondents to the question "What kinds of decisions do you remember related to health care and who was responsible for these decisions?" Some of the answers show a belief that access to health care was not an issue and a lack of awareness that racism may have factored into the care they received from the health care system. In referring to visits to the doctor, Kim stated:

> "I think it was very important uhm... in our family. I can remember several visits to the doctor's office for well checks, and any time, sniffles, whatever, we-we got a lot of health care growing up."

This passage illustrates Kim's awareness that while growing up her family made decisions to seek health care for a variety of reasons.

Kim also remembers her mother's attention to her own personal health.

> "And I think uhm... my mother was very good about going in and having all her screenings and being checked and having all her-- didn't like 'em, but always made sure that, you know, had a calendar and knew when it was time to go in and have all of this stuff done."

These memories illustrate that while the historical times of the 1960's and 1970's were difficult for African

Americans in terms of access to health care, Kim believed that her mother was able to obtain regular examinations. In the same historical context, Coffy remembered growing up in an African American neighborhood in Chicago where her family had access to a wide range of health care providers. As a child, she was unaware that her friends and others in the neighborhood may not be experiencing the same access to providers that her family experienced.

> "I don't know. It wasn't- It really wasn't uhm... necessarily a- a big issue. We- we had, when I think back on it, I guess, and when I think back on it now, I guess we were more privileged than I thought we were. Or whatever, but, we had uhm... had a family doctor. We had a family pediatrician. Uhm... My mother had uhm... her OB/Gyn, actually was my OB/Gyn. Uhm... Had delivered me, you know. And she went to him, you know, annually. My grandmother went to him. Uhm... The pediatrician, I remember, we would go to him all the time. You know, so, if we had a cold, or whatever. And so, it was like a family person- And we actually had like a family dentist, too, that we would go see. So, you know, I- And I think I took it granted, probably thought every- all the other kids were doing the same thing."
>
> Coffy

This passage illustrated the wide range of providers to which Coffy had access and lack of awareness of the racism indicative of the times. She also indicated that she had no awareness of a difference in her experience from that of her neighbors.

Maya also recalled access to providers for all family members. Maya's mother worked for several of the providers. This afforded extended family and friends access that was not available to all members of the community.

> "Anyway, we did have a physician or doctor where that-- I remember this so plain because I was at my dad's house, my mom and dad divorced, and I guess I must have been about maybe 12, 11, and I was very ill and I was laying on the couch and doctor's were still making home visits then. And the doctor came to the house…"
>
> Maya

This passage illustrated that the event of divorce did not influence access to health services, even when Maya was at her father's home. Also, her mother's employment benefited the family through access to health care services.

Sojo's mother also worked for health care providers and lawyers who afforded her access to resources and a level of knowledge regarded by others in the family as expert. In reference to her mother's health and work Sojo stated:

> "…Meant sickness and for me especially I would say my mother not being able to get to work on time defined health in my household because my mother was the person who worked with the doctors and the lawyers and she would be the person you'd contact to say Jessie…Bob is sick."

When asked to expand on how her mother's employment influenced access to physicians, Sojo said:

> "Because she went back after she actually did retire. She was involved in community service and getting information out to people. So, in the end of her life, the oldest daughter, yes that did occur. But in the meantime, I think due to the age they grew up in,

> certainly my mother had access to doctors back in from my birth was in the '50s. So she had access to doctors."

This passage illustrated awareness on the part of Sojo that during the 1950's her mother's position provided the family with access to health care services. In addition, her mother had access, through times of transition from work to retirement and the event of death, to health care services because of her work experience.

Sojo went on to describe the racial identity of the providers, saying:

> "At home visits, you know, so they would do that and they were not African-American doctors. I can't recall the African-American doctors that were in the community that she was dealing with. She was dealing with White doctors that would come to, you know, our family's homes based on what she would say to him and he would come."

This passage illustrated Sojo's family did not experience racism in terms of access to home health care even during historical times preceding the Civil Rights Movement. It is not clear if the experience would have been the same if the family required hospitalization or expensive treatment. Two of the respondent's referenced racism or a sense that racism may influence access or the decision to participate in health related services. Maya's memories were associated with the feeling of control on the part of providers and outcomes for failure to follow direction. The "they" in this passage refers to doctors in general. Maya stated, in reference to her mother:

> "But she had a strong belief that we had to do what the doctors told us to do, otherwise, there would be bad things that happened to us. That was always engrained that they have control of our lives, and we needed to be submissive when we came into that environment."

The historical times Maya refers to are the 1950's and the 1960's. Maya went on to share an overall sense of mistrust that was associated with interactions with providers. She stated:

> "Yeah. The reference that was made to a person becoming sick is that their-- Okay, if they had a surgery, they would say, "Well, you know, they opened him up." And, you know, when they open you up, that's when it spreads. So, that was frequently referred to. The other thing was, I don't know what's in the food, but it's killing all of us. And they referred to different, I guess, genocide or plots, society plots. <laughs>".

When asked if Maya or her family had experienced anything similar to this description, she shared her view of the importance of perception regardless of personal experience:

> "…I never heard my family say that they witnessed any bad medicine or knew of personal experiences. I think they all had heard or believed experiences occurred. For a Tuskegee incident, for example, that really didn't get out until the '70's. And that's when it actually came into print. And so, I don't know how many people-- There was a perception-- And I think that's one thing that you talk about. You can't take a person's perception away. And often times, there's a perception about people that we enter with that you

> don't even have to say a word…Even when my grandmother said, and she would say, do you know they can kill you, was her way of saying that, I know they'll kill you or I seen them kill people or whatever, without speaking about it, to know that it has occurred. But just informed me of a potential when you didn't do, and they related to, if it wasn't done, if you didn't respond to what was asked of you, you could be the recipient of something that would be a negative outcome."

Maya came to understand that historical events happening to other African Americans as a result of racism could also happen to her if she responded inappropriately to what you were "supposed to do".

Maya went on to describe a form of racial socialization that related to access or interactions with providers. In this passage, "they" refers to providers. Maya stated:

> "For my parents, I guess. But, you know, they knew still-- And they were imparting it to me that he still had the responsibility for your life… Didn't matter what his color was. That position had control. And that's what they were trying to-- It was the control. Cause I have no control of-- And they didn't, what a physician could do…"

Maya's parents imparted the perception of control on the part of providers indicative of the historical times.

Sojo's reference to racism was less detailed, but demonstrated a level of awareness that her family's access to health care was unique.

> "Yes, because I, you know, I don't know. I don't know how the access to medicine was back in the day but I think sometime depending on your color maybe you didn't get in the door."

Sojo

Sojo understood that the historical times influenced access to health care for African Americans.

The White respondents shared different, more carefree memories of accessing health care services, with two referencing memories of home visits by their doctors. During these historical times, it was common for doctors to make house calls.

> "Well my Mom is just like I am, she was a nervous person about everything, if you had one little thing you were, you know, we had to go have it checked out, very overprotective about my health…but we always went to the doctor, we always had our checkups…he made house calls, he, you know, and he knew our family history and all of our medical uhm... Problems and just uhm... My Mom was really into that."
>
> Amy

Amy learned to access health care services for a variety of problems and grew to know her provider well.

Hayley too, recalls home visits from her family physician, stating.

> "He made house calls. He would come in the house and take care of us if we were sick."
>
> Hayley

Across the life span, each participant experienced access to health care, with some of the African American women having access as a direct result of their mother's work and others hinting at racism, indicative of the times. Divorce as an event, was expressed by a number of the participants.

Life course and divorce

Six women experienced divorce as a life course event. Several of the women came from divorced families of origin and also experienced divorce in their adult lives. Coffy was one of those women who described her life as a child of divorce in this way:

> "as a child in elementary school, we lived in a two-flat apartment building… half-way through eighth grade, we moved into a house. And my parents had divorced when I was about 10 or 11, and uhm... and so, it's like- Yeah, we had- we had a roof over our heads, you know, parents worked, so there were some things we had, but we didn't have a car. You know, we- there were some things we didn't have, but it was expected that you know, we went to the doctor. We went to the dentist. You know, so those things, I just- I took for granted."
>
> Coffy

This passage illustrated that even in divorce, the family sought out health care services.

Along with her own divorce, as an adult Coffy experienced the event of the deaths of her three children due to a rare, genetic disorder. Coffy described these life course events:

> "My- my faith has sustained me through life, but it's also ve- very active. Uhm... It- it's sustained me through uhm... oh God, traumas and- and uhm... Probably something else you didn't know either, I uhm... After undergrad, I- I got married a year later, and in my- during my marriage we had three children. And each of my children were born uhm... Premature, uhm... They were born with some very rare, unnamed syndrome. And they each lived to be well- They each lived to be at least a year old, uhm... One son lived

> to be three years old. And they died as a result of this syndrome that proved to be uh... Fatal. And which is one of the reasons I'm divorced, because of just having to deal with that."
>
> Coffy

During the life course events of divorce and death, Coffy used faith to make sense of what she was experiencing. Rose shared memories that may be more indicative of African Americans during the 1950's and 1960's, and the experience of stressed mothers overall, who seek health care for their children and not themselves (Campbell, 2000). Rose stated:

> "My mother, I would say was the biggest person, and she still is the biggest person on health and taking care of yourself. And although, you know, she couldn't afford it she still made sure that, you know, we were, you know, we seen the doctor regardless of what it may have been…"

Rose indicated awareness that her mother could not afford personal health care but not an awareness of lack of access because of their racial identity.

Rose went on to say:

> "But, you know, I don't even recall her going to the doctor. You know, and I'm sure she had to go to the doctor…"

It should be remembered that Rose's mother experienced the event of divorce and transition to a remarried family that may have influenced her mother's decision to access health care.

Maya described her first marriage as a troublesome time that ended in divorce and remarriage, stating:

> "Yeah. I guess I would have to say, although I told you about my leadership and whatever, I had a very horrible first marriage, and this was the father of my children. And I remained married for almost 20 years, 18, 19. And just getting out of that and surviving that whole, what do I want to say, turmoil. It was phenomenal to have survived in that relationship and be the person who I am."

Sojo remembered a different experience with the separation of her parents and their ability to remain cordial and supportive of Sojo throughout her childhood. Sojo stated:

> "Together. My dad came to our home every day. My mother left a lunch for him but they didn't live in the same household from the time that I was 13 until; well I left for school at the age of when I graduated high school. So, he came there every day and he was a part of our lives but they never divorced."
>
> Sojo

Sojo went on in adulthood to choose common law marriage rather than a formal marriage. This partnership functioned as any marriage in terms of roles and responsibilities for both even after the relationship dissolved. In describing her common-law marriage, Sojo stated:

> "That lasted up until I would say that Kelly [ph?] was about -- maybe eight years of her life. We were just like I guess we grew up that we didn't need marriage…We had each other. We had things. We had I had some college background. My partner had a college background…"

This passage illustrated that for Sojo, the dissolution of her common-law marriage was similar to divorce experienced by others.

Amy's parents remain married, but she described her own first marriage as a response to the arrival of siblings within her family of origin, a transition experienced traumatically by Amy:

> "Well I know exactly what-what happened, I was an only child for ten years and my parents, you know, had two other children, my-my sister was born when I was ten and then another s-uh... sister when I was thirteen, and they were raising kind of an-a two separate families and they're great parents and they're wonderful parents and they gave me everything, love, uhm... anything I would've wanted financially, they would've sent me to college, but I kind of got hooked up with a guy, uh... I did get hooked up with a guy, because I feel-I felt like I was, you know, needing uhm... attention from someone, because they were busy with their little family, …So I met this guy and ended up getting pregnant and uhm... I did graduate from high school but then at that time we got married and then-and that's kinda what happened, and then I never-and then went through a divorce, we were married for eight years and I didn't go back to school, I was busy re-raising our son…"

Twice divorced, Cissie recalled the life course events associated with motherhood and step-motherhood, and the decision-makers related to health decisions.

> "And then I divorced her-- we got divorced when she was-- when Jordan was two, and I got remarried when she was four. And it's-- having two step kids and a daughter, there's such a strange dynamic of who's involved. But generally I would say that the mother of my stepchildren was more involved in making the

> health decisions for them. I was the one in charge of making the health decisions for my daughter."
>
> Cissie

Cissie intimates by describing the "strange dynamic" that the transition from a divorced to a remarried family was difficult and required the making of compound decisions.

These responses illustrate that some of the women have experienced the life course event of divorce either through personal experience or from their parents. They each have experienced transitions from being single, to being married, or remarried, and from having no children to having children. In some cases, the women discussed the blending of families in the event of remarriage.

Historical influences from a life course perspective were most evident among the African American women who described the perception or experience of racism during their childhood years. Whether these experiences influence their participation in breast cancer screening was mentioned only by two of the participants.

Participation in breast cancer screening and life course

Having access to health insurance through one's own work influences a woman's ability to participate in breast cancer screening. Divorce is one life course event that affects access to insurance for many women. Sojo was the first to mention the relationship of insurance to her ability to have a mammogram. Sojo stated:

> "But then they told me my insurance said, "No." Unless there's a risk of it in your family. And they had me do this little thing, and there wasn't anything to prove that then. So, they wouldn't pay for it, and I couldn't afford to have it done. And I don't know of any programs back then that was trying to do that."

Sojo had health insurance but the health insurance did not cover mammography for a woman her age. Single parent responsibilities and cost prevented Sojo from paying for the service herself.

Cissie recounted her experience related to lack of access to breast cancer screening during her second marriage. She and her husband worked in a private business and therefore she did not have health insurance. Cissie stated:

> "I used to get so mad, I couldn't afford to pay for a mammogram and here I am, at risk because my mother had breast cancer, and I can't even get it…the cost of paying for my husband's daughter's asthma affected our marriage…I thank God everyday that I now have health insurance through my job and now I can get a mammogram every year."

This passage also illustrated the decision to choose health care for children over personal health care.

In answering Research Question Three, "What are the effects of life course transitions and events experienced by women and their participation in breast cancer screening" it is clear that all participants experienced events and transitions in their childhood and as adults. It was less clear that these events and transitions affected the respondents' participation in breast cancer screening except in the cases of Sojo and Cissie. In these two cases, the lack of insurance played a part in their inability to participate. Thematically, the respondents mentioned accesses to health care and/or health insurance throughout the life course, but only those two spoke of transitions and events that affected their participation in breast cancer screening.

Objective Two

Research Question Four: "What family related factors do women consider when making the decision to participate (or not) in breast cancer screening?"

To answer this question, the respondents were asked, "Have you scheduled your mammogram" and "In the decision to participate (or not) in breast cancer screening, tell me the factors you considered." Because these questions are closely related, they are presented together.

Without exception, all respondents had or were scheduled to have a mammogram. For some, the responses to the question were brief.

For Kim, the factors considered were technical, much like the way her mother responded to health in her family of origin.

> "Uhm... I went in for my physical. She did my thing. She told me I needed a base-- she'd prefer I go in and have a baseline. And I just said, "Okay.""
>
> Kim

Kim demonstrated an understanding of the need for a baseline mammogram as part of a normal physical but did not mention family related factors in her decision.

Coffy had a different rational for participating because of a recent diagnosis of breast cancer. The factors she considered were complicated by mixed messages related to the treatment course and her decision to have only a lumpectomy rather than additional therapies. It should be noted that Coffy was diagnosed (in situ) her conservative decision was appropriate for this type of early stage cancer.

> "Yeah. That's all-that was another reason too, it's like "Okay you're telling me I don't have to come back in until next year for my annual [mammogram], but yet here's this oncologist "Oh no you've gotta come in so I can pump you full of"", that's like "you've gotta be crazy", if-if he's the one telling me, and this is the one I'm seeing and even my family practitioner here, she was just like "Oh I got your reports" 'cause I-I asked her about it, she said "Well I-I got your reports, I'll see you in-in the summer". S-so I just felt like well, I think you all know me a little bit better than this person that just looked at this chart and made it seem like "Ooh, another guinea pig", I just thought "No, I'm not having the treatment" and…"
>
> Coffy

Coffy described her confusion about the appropriate timing of her mammogram and ultimate decision to have a yearly examination. Coffy does not mention other family related factors in her decision to participate.

Maya's decision to have a mammogram was based on time and access related reasons:

> "I was due, and that it was a convenient location, and that although it wasn't in a breast center, I felt that it was time and I was comfortable with that decision just to have it done. It was time, so…"

The results of the mammogram were positive for an abnormality. Maya was faced with the possibility of breast cancer. She stated:

> "Well, I must tell you, I had my mammogram last month-- no I didn't. I had my mammogram last September and that showed a lump. So I'm having a needle biopsy on the 19th of February that I didn't tell you about."

Maya described decisions to participate in breast cancer screening that were made based on her perception of need rather than family related factors.

Sojo considered her health and environmental factors from her past work experience in the decision to have a mammogram. She stated:

> "Well, you know, one thing is just because ever since they told me I was a diabetic back in '95, I just thought, "You better me more conscious of what's going on with you." …I worked in a factory before. I don't know what that stuff did to me. I was around a lot of toulene [ph?], I think you call it. Heavy duty chemicals and paints and different things. So, I

> don't know. I was a smoker in the past. And I don't know. Like I said, prevention. I want to be on top of it."

Sojo's belief in prevention played a major role in her decision to participate in screening, without mention of family related factors.

Rose provided a simple response that may be related to her experience as a child in feeling disconnected from her family. Rose stated:

> "No, I've just put it off. I just put it off. And I can't give any reason other than, you know, I'm always putting other things before me, pretty much."

The "other things" Rose referred to are the needs of her children, who have been described as having health care needs of their own. Rose was the only African American woman to specifically mention the needs of others in reference to her decision to participate in breast cancer screening.

The White women also shared the factors they considered in the decision to participate in screening services, many with a focus on their personal need, either physical or emotional. Additionally, some expressed recognition of a fatalistic viewpoint expressed by some of their friends who have not participated and recognition of the benefit of early detection. Amy stated:

> "I need to do this because if I'm-- it's gonna give me peace of mind when they tell me I'm okay. And if I'm not okay, I need to know so I can fix it early and get it caught, get a jump on it… Uhm... but basically to do it, you know, I know some people think if they don't do it, you know, that, "I'll never have to worry about it," ……But then I think, you know, if they do, then good, because that's a good thing. Because then we'll get it fixed. And I'll have a better chance than if I didn't do anything."

Amy described the value of having a mammogram in discovering breast cancer at an early stage but did not mention family factors in her decision to participate. Although vague, Hayley intimated the idea of early detection when she stated:

> "Oh, I-I just wanta make sure that uhm... they don't see anything and just go in and–"

Hayley did not reference specific family factors in this reference to early detection.

Bambi approached the response from a philosophical stance that probably comes from her childhood experiences with the meaning of cancer.

> "I think about my quality of life, and what I want from life, and if I get my screening and I was to have, you know, a-a tumor and we had to do a biopsy I would not wanna do it but I would do it, because I wanna know, and can it be removed and I would take the steps to take care of it, because I wanna be here when I'm sixty, I wanna be here when I'm seventy, I wanna see my kids have kids and I wanna see my grandkids grow up, and I wanna be there for my grandkids, you know, I want them to, you know, wanna come see me and I don't wanna just, you know, "Oh gee I have cancer, I'm gonna die", I don't wanna die, you know, I wanna-I

> wanna live. So that's why I do it, and I wanna live well, I don't wanna live bad <laughs>."
>
> Bambi

Bambi's response also indicated a consideration for family related factors in her decision to participate and the roles that she played within the family. This was expressed as her desire to see her grandchildren grow up. She also expressed a desire to have a certain quality of life with aging.

Describing the factors she considered in her decision-making, Cissie's response was indicative of her academic upbringing.

> "Well, I definitely, you know want to make sure about uh... being in control of the variables I can be in control of. So uh... especially since mammograms are fairly -- they're fairly easy test to get and I hear all this stuff about, well, they're not that effective, blah, blah, blah, but you know, until-until the majority or you know opinion moves to say that, okay, they're not worth that much. I just hear too many people say that their- their cancer was found by a mammogram, so that's effective enough for me. So I'm going to continue to have regular mammograms."

Cissie's response illustrated an awareness of the value of early detection without reference to family related factors.

Yvonne's response was simple, but indicative of the power of access to providers and insurance.

> "<Laughs>. Well I pretty much do it because my physician says I should do it. Although I just did read something about the fact that it's probably not

> necessary to have it yearly. But as long as my health insurance pays for it, I don't really see a reason not to."

Yvonne's explanation for participation in direct relationship to having insurance is clear and to the recommendation of her provider. Family related factors are not mentioned.

In response to Research Question Four, only two respondents directly mentioned other family members as factors considered in their decision to participate in breast cancer screening. Others mentioned that they were "due" for their yearly mammogram that alludes to a life course transition related to aging and considerations relative to health.

Considering the family ecosystem, several mentioned having health insurance as a factor associated with their decision to participate. Others discussed their provider as influential in their decision-making. This relationship represents a social/cultural environmental interaction. Having access to mammography units represents the human built/technological environment that enhanced access to care for these respondents. Thematically, access to appropriate health care services continues as a factor associated with breast cancer screening. Over the life course and with increased technology, access to health care expanded from having a provider to also having the insurance to pay for appropriate screening.

The last section of this chapter addresses Objective Three and the research questions used in responding to the objective.

Objective Three: To explore individual attributes of women aged forty to fifty-five, which reflect culturally specific attributes.

Research Question Five: "How do women perceive their family relationship, life course transitions, and events as influential in their decisions to participate in breast cancer screening?"

This question explored the influence of culturally specific attributes on general health care decisions and screening services. It should be noted that throughout the responses to the other research questions, participants have revealed cultural relationships within their family of origin and their current family. These include the behaviors learned through direct communication with their parents or through observed behaviors that they adapted and use within their current families. Their value of health and beliefs to obtain health all represent cultural behaviors. Relationships with their mothers and the information their mothers shared with them represent cultural belief systems. This section explores additional comments that focus on perceptions of family relationships and the life course on decision-making.

The questions were constructed to discern how the information learned in the family of origin translated into current family experiences and whether women had a sense of their own health needs in relation to their family.

Current family health values and beliefs

The purpose of asking the question "How does your current family define health" was to determine if the women used behaviors learned from their family of origin with their current family. It also was intended to determine if women included a sense of personal need in relation to the family.

Kim described her definition of health as discussions that are similar to her experiences in her family of origin:

> "Oh, hmm. I think we talk about it quite a bit…So I kind of-- it's pretty open discussion uhm... at our house about health and health in general. And I don't know if it's because I work in the health care field and just kind of knew these things. But I'm amazed at some of the things that comes out of some of my kids' mouths. That they say-- that are health-related, that are-- that are health-related. And it's uhm... the remarks kind of fly back and forth and they'll get on their dad about his salt and his blood pressure. And stroking out's another thing that's used quite commonly in our house."
>
> Kim

Different from the experience in her family of origin, Kim's children have learned health-related facts outside the home that they bring back and share with their family. These comments demonstrate a sense of awareness of the relationship of another's health to the family.

The definition used by Coffy to define health was practical:

> "Again probably the-the fact of being able to get a-get around and-and uhm... uh... you know, it might not be necessarily disease-free but uhm... trying to eat the right things, being able to n-not having I guess some chronic disease or anything, being able to basically get-get around and do things, and-"

As in her family of origin, Coffy defined health as it related to eating properly and avoidance of disease.

Maya defined health holistically:

> "Well, I define health as being in your optimal state of well-being, mental, physical and spiritual."

As in her family of origin, Maya's definition focused on personal needs but not in relation to the family.

Sojo describes her definition of health in relationship to prevention and recognition of the need to seek information. She also identifies barriers to obtaining health for African Americans:

> "I just see that we have a lot of ways of being that are preventing us from being healthy…It's also that

> prevention is a key to being healthier…But I guess we didn't know how serious health could be, or how we should be attending to our health…I want to prevent a thing from happening now, as an adult I can see that there's more information from the medical side that can show you ways to prevent things from happening. And also dealing with the denial. And especially being African-American, I don't know all the reasons why, if it's access to care, if it's what we're concentrating on to get ahead in our lives…"
>
> Sojo

Sojo goes on to describe the active role that African Americans must take to achieve health:

> "…But we are not bringing the issue to the table. We're not attending with the issue once we've come to the table and realized how dysfunctional we are about it in our community. I can't see my daughter's generation being in that situation…We don't have to be…So, I'm just totally in that kind of a mode. Information and what to do with it and let's make the outcome a success. So, that's how I look at health now."
>
> Sojo

Sojo described health in terms of personal responsibility, and she identified the relationship with her community of African Americans as important in terms of health.

Rose described a prevention related definition of health learned her mother. This was learned when Rose was an adult rather than as a child.

> "I think I've become my mother now with my kids. It's like, you know, the least little thing, almost. You know, you need to go get that checked out, especially if they're, you know, constantly complaining about it. …But now that I've got at least health insurance, you know, I'm more apt to say, you know what, lets go and look into this and see what's going on, you know. And I'm always, you know, thinking, you know it's

> better to catch it while it's early rather than wait until it's too late…"
>
> Rose

While Rose's mother infrequently discussed health, her mother currently spends a great deal of time discussing health, and Rose adapted this pattern with her children. This passage illustrated the relationship between prevention and health as important factors for each member of the family.

When Amy described her current family definition of health she did so in relationship to an awareness of her own mortality:

> "Well I think whenever your body goes through changes, like when I went through my change of life I decided that…that something--not that it wasn't good, but that-when there's a change like that uhm…that's when some things can start happening in your body. So that educated me to uhm…And that's when I realized that you don't just get an okay bill o' health one year and it sticks for the next year, that's when it started clicking with me that, you know, things can go wrong, you have to continually uhm…be on top of things, because if you're not it could be something that could come up".
>
> Amy

Amy's current definition of health challenged the definition of health she learned as a child; "If you have your health, you have everything."

Hayley's definition of health was as vague as that earned in her childhood:

> "It means keepin' your body in shape and just stayin' alive."
>
> Hayley

When pressed for further explanation, Hayley recounted messages learned as a child:

> "Tryin' to just eat right and, you know, try to eat right, eat some healthy things and uhm... I don't know."

The question was difficult for Hayley to answer, and the response lacked an awareness of the relationship between personal health needs and the family.

Bambi described the definition of health used in her current family as one that focused on specific facts related to nutrition and exercise:

> "Well I guess <laughs> I would have to say I'm lo-and I-and I wouldn't be able to even tell you what the good numbers are, but, you know, you gotta have low cholesterol and a healthy blood pressure and uhm... not obesely overweight, uhm... that you exercise, that's what I would call health."
>
> Bambi

This passage indicated a difference in the health definition she learned as a child, where health discussions were vague and implied rather than clearly identified. Instead, Bambi focused on behaviors that are personal needs, but not in relation to the family. Bambi goes on to say:

> "I-I am pretty-my kids were raised because I was more health conscious, my kids were raised that, you know, you have to drink your milk, you gotta have some

> vegetables…and the kids know why, because I've said, you know, that's not good for you…So my kids-I've raised my kids and-and we're pretty open about it, as far as personal health issues I'm more like my mother and my father, if I had uhm... if I have to have a test uhm... I've had-I had a-a biopsy, I don't even think I told ___, you know, I mean that wasn't breast, it was, you know, down there but, I don't think I shared that with him"

In this passage Bambi admits that she did not think of her personal health needs in relation to her family or her husband, reverting to behaviors learned in childhood. Cissie admitted to the same health description learned in her family of origin:

> "I passed along the, 'If you don't have a temperature, you're going to school.'"
>
> Cissie

The practicality related to health for personal responsibility continued in Cissie's current family. Some of the messages were unchanged overtime. Yvonne described a definition of health that was similar to the message she learned in her family of origin:

> "Uhm... eating well, sleeping, <laughs> getting your rest, getting lots of exercise, uhm... making sure that your- your health issues are taken care of promptly."

Again, the need for personal responsibility was part of the health definition for Yvonne.

While many of the women have expanded their definition of health to include the perception of prevention as part of personal responsibility, only messages related to nutrition and rest persisted as behaviors learned in the family of origin. None of the women described cleanliness or dental care as essential components of health. Along with prevention, exercise, obesity, and particulars like cholesterol and blood pressure were identified as indicators of 'health'. The definition of health has changed over time, with some women indicating this change resulting from increased access to knowledge.

To understand if the discussion of health included a message of personal need in relation to the family, respondents were asked how they discuss health in their current family. Kim praised the knowledge obtained by her children through the school system and acknowledged the role this played in family conversations. She also indicated a continuation of the health behaviors she learned from her mother:

> "Well actually, because they've all had to take health classes at school, they all have this general knowledge of stuff. And I think kids at certain ages are just more inquisitive about something. And we have a pretty open conversation policy that we can pretty much talk about anything. And anytime anything comes up health-related, and sometimes the kids will bring it up, or they heard something at school and they didn't think it was quite right, so they'll come home and ask me if, "I heard that blah, blah, blah. Now is- is that true?" And it usually sparks a-- sparks a conversation about health or health-related issues. And I think I might have picked up some of my

> mother's tendencies, but I'm always, "Put your hat on, you know, put your shoes on. Don't go outside. Cover up your nose. Don't breathe in all that cold air." And so I think they get a-- they get a full dose of it."
>
> Kim

The health messages clearly indicated a focus on personal need, but did not describe a relationship between the individual and the family.

The health discussions described by Coffy focused on personal activities:

> "Oh weight and getting a-getting weight under control uhm..."

Health defined and discussed within Coffy's family of origin and her current family experience consistently carry a theme focused on the relationship of health to eating and weight.

Maya identified a change in the discussion of health between her family of origin and her current family. She stated:

> "Yes, …I mean HIV?…I think I told my daughters. I said, "You know, when I was a young girl growing up, I think that what my family or what my mom tried to introduce to me was that you don't let anybody touch you down there, because you might get pregnant,"… And I said, "You know, that's not what you need to be concerned about today." I said, "Today if it was a baby that meant something," I said, "That's a good sign." I said, "What happens now is that when you get into intercourse and just experiencing with sex and you're not married," I said, "That sets you up for death." <Laughs>.

This message illustrated a change in the content of the message that continued to be directed toward personal responsibility and health needs.

Sojo also noted a change in the discussion as a result of increased access to information. Sojo stated:

> "Now, it's all open. We all are on the Internet. When we do get together-- as a matter of fact with our last family reunion-- because it was the year 2000, it was coined "Heritage into the Future." What's our responsibility? Because all the older people now is getting down to us in our 40s and 30s to run this whole affair. And so what do we want it to reflect? Just a good time and lots of food? Or some information about what we do know that our family has a history of diabetes. We have histories of hypertension. We don't necessarily have histories of cancer, but there have been problems with that and different things, so what do we want to know about it? Are your children being immunized? And certainly we have lots of people now in the family that are in medical fields, so share the information. Tell the things that are available. And so that was one of our project to make sure."

This passage also illustrated a clear understanding of the relationship between personal needs and the family. In this case, Sojo described the importance of sharing health information with her extended family.

Rose described a change in the conversations. Rose stated:

> "It's open. Our conversation now is open, and the reason it's open is because it was so closed for me in growing up. You know, I was just so ignorant to, you know, things that I didn't know. And so whatever is happening or going on with anybody in the family, hey lets sit down and discuss it. Lets talk about it and see, you know, what we can find out. So it's an open discussion. And they know pretty much, you know, if

> they have a question, you know, we can do and do some research and find out."

Rose indicated deliberateness on her part to make a change so that her children did not have the same experience as she did. She too indicated an understanding of openness within the family related to health discussions.

Amy recounted a story that indicated a lack of communication related to personal health needs and the family from an experience with her husband. Amy stated:

> "I'm really a nervous mother about anything, I'm the one in the family that prompts everybody to go to the doctor, I mean I had to tell [husband], he had a lump in his testicle that he had-didn't say anything to me about it, but he-he had it for like a year and a half, and he never did anything about it,…And I made him go… and he went and finally got a physical…and [doctor] said that's just the scar tissue from your uhm... your vasectomy. And it's like "Why didn't you do that the minute you felt it, why would you put yourself through that worry and then if you don't have to worry if it's nothing, it's nothing, and if it's something, then you get it fixed right away and you have a better chance?"

Amy expressed frustration in this action but did not indicate that her husbands' failure to seek health care had any relation to the family.

Hayley described deliberateness in not openly discussing personal health needs within the family. She stated:

> "Probably uhm... probably all of us. Like we include [children] you know, pretty much everybody if it's concerning them. If it's us goin' to the doctor, you know, we really don't say much to 'em but uhm... just try to get them to stay healthy.

While the discussion prompted the children to "stay healthy", there was no indication of the relationship between personal health and family.

Cissie mimicked the "practical" component of the messages learned in her family of origin. Cissie stated:

> "We are very practical and I try to make sure that she understands how important-- well, you know, taking care of yourself is, in terms of-- of course, you can try to tell your kids that they actually do need to sleep in order to stay healthy…You know, eat right, let your body rest, get some exercise; all those things that we know is smart…you know, and some of the stuff that I've told her about those kinds of-- the cause and effect kind of things."

Cissie also noted a change in the way health related information was discussed in her family of origin compared with her current family. Cissie stated (in referring to her daughter):

> "She's starting to realize that it is true…And I've been very open about, you know, when she's-- I've been trying to say, "When you become sexually active, please let's get on birth control."…And our generation is in general much closer to our daughters than previous-- than we were to our mothers, that's for sure. So-- my mother still won't accept the idea that I've actually had sex, you know, almost fifty, "No, we don't," you just don't even think about that."

While more open in the topics discussed, there is no indication of concern for personal needs in relation to the family.

Yvonne described a similar pattern learned in her family of origin. Yvonne stated:

> "Uhm... we talk about eating the right foods and getting the right sleep…Uhm... we talk-- I talk a lot about exercising, but I don't push it on them particularly."

Yvonne clearly credits the mother-daughter connection when asked to talk about the similarity. Yvonne stated:

> "Oh absolutely it came from my mother. But I think there's a lot more information out there now too that-- and I get regular publications from my health care provider, uhm... from my school that I teach at, about those kinds of things. So there's a lot more things to read about now than there used to be. But I think the basis came from my mom. Yeah."

Yvonne acknowledged her mother's influence and the influence of access to information. Respondents were asked if they used sayings or adages to impart health information within their current family. Most respondents focused on the dissemination of nutrition related messaging that mirror their definitions of health.

The respondents were asked to describe who was responsible for health in their family of origin, who is responsible for health in their current family, and to describe the differences. These passages illustrate the ongoing role of women as responsible for family health, which remains unchanged across the life course.

Kim described her belief that she was the responsible party for health decisions in her family, stating:

> "I think I'm-- I think I'm responsible for the health-related decisions in our family. And- and I think my mother ah... my mother was pretty much-- because she was-- she was home, she was an at home mother, so she was home and she made all the decisions."
>
> Kim

Kim also indicated that this role within her current family was similar to that same role played by her mother in Kim's family of origin.

Maya succinctly offered her opinion, stating:

> "It's still the same. It's the women."

While not directly stated, the use of the word "still" indicates that women have been the directors of family health across the generations within her family of origin.

Amy described a similar belief related to role responsibilities:

> "Probably. I took that role, I'm sure. I'm sure I did…A man, woman thing. I think men just don't-- at least the men in my life, my dad, my grandpa, my husband, my son, I don't think they're-- maybe they think about it, but they don't verbalize it as much. You know, like ____ will tell me he's got a cold or something, but-- whereas ___'s just-- more borderlines on a little bit hypochondriac I think."
>
> Amy

By comparing intergenerational attitudes of the men in her family, Amy indicated health is considered within the woman's role.

Bambi identified transitions from single to married and then from married to having children when she discussed the changes in role responsibilities from her family of origin to her current family. Bambi stated:

> "…so it was Mom's responsibility to take care of the kids and not Dad's. Where ____ and I both have always worked, although I had a little more flexibility in my being able to leave work because that's how I approached my job, it's like well, you know, I'm responsible for the kids, so that's how we approached it and we, you know, that was what we agreed upon when we got married is, you know, you're gonna share things, back then, you know, you got married, husband-wife, husband duties, wife duties <laughs>, and those aren't defined like that now."

This passage illustrated that in terms of marital relationships and role responsibilities; Bambi noted a change from her family of origin.

As described by the other respondents, women in Yvonne's family were responsible for family health.

> "Uhm... certainly I think the- the woman in both my families growing up was- was the guardian of health. But I think that my physician is a lot more active, or I'm a lot more involved with my physician that I used to-- than I was when I was growing up. You know, I don't remember going to the doctor a whole lot when I was growing up."
>
> Yvonne

Yvonne also described changes related to patient/physician relationships that have changed over the life course, with closer involvement noted.

Respondents were asked to compare and contrast the discussion or view of cancer and cancer screening within their family of origin and their current family to determine if life course factors influenced their decision-making.

Kim described differences in the discussion of cancer that is related to a better understanding of cancer. Kim stated:

> I think the difference is uhm... cancer has a name. I know-- I know-- I'm gonna say I know about it than maybe my- my parents did. So uhm... when we discuss it, it's more on a educational basis, or in- in the conversation…And so we- we talk about it. And I think as far as-- it's more for a- an educational type thing to just make your kids be-- make my kids be aware of it,…it is a sickness, it is an illness, it's nothing that that person did wrong to get it…And that uhm... yeah, it's a bad thing, but there's- there's treatments out there."

Along with putting cancer in a positive context, Kim related how she has used the positive attitude learned from her mother with her current family, and that across the life course; the message has changed very little. When describing the discussion of cancer screening with her family she stated:

> "I think with me and my mom, I think she put that importance in me, and I've tried to relay that over to- to my family. So I think we discuss it. We discuss it real open and honestly."
>
> Kim

This passage illustrated a deliberate effort on the part of Kim to provide her family with a positive message that seemed unaffected by life course transitions or events. Coffy described her impressions based on her current diagnosis of breast cancer. Coffy stated:

> "Probably about the same…but I don't know, I d-it's-it's not like it's this whole panic and everybody let's go and do it 'cause, I mean my mother was going to the doctor on a regular basis and my grandmother does, yeah it's just stuff like this-this happened and what can we learn from this. So it's-I can't say it's like a-a panic or an uh... of a worry or even like a paranoia because of it, it's just more or less like this happens."

This passage illustrated a rather fatalistic viewpoint when Coffy stated "…it's just more or less like this happens". This viewpoint has persisted over the life course. Maya described differences related to having access to providers. The difference is a change in the perception of trust that her family now experiences compared with her family of origin. Maya stated:

> "We have open communication. There's dialogue. And then I guess there's-- if you don't know something, you have other people that you trust that you can go ask that we didn't have probably in the early days when they were getting us doctors or saying doctors were gonna do something different to us or whatever. I think because of-- yeah. I think you have more people that you can trust and depend that they're gonna give you a high quality service. And then you have information and education and resources that if you don't agree, you can disagree and look elsewhere. <Laughs>."

This passage illustrated changes that have occurred over the life course that lead to an inability to trust physicians. Maya went on to say:

> "Well I think there's more effort, yeah, today than what they were when I was growing up for health screenings. So definitely we're discussing more outwardly and having open conversations about that where it wasn't-- as before it was secretive…But now, you know, we talk about it, we're just informing one another, but what we learn of the access …so we really need to be really aware and making sure that our children have that information and their children have that…"

While not specifically identifying transitions or events, Maya acknowledged the changes that have occurred over time across the life course.

Sojo described a life course event related to her uncle's diagnosis of cancer and the thoughts people had about the disease. She stated:

> "People used to think that cancer would jump off on you. And not touch. And I think certainly my uncle, he felt more comfortable with my mother, because she just-- I can see them sitting together on that sofa and being so loving to each other, where everybody else was like shying away from him."

Sojo learned from her mother that cancer was not to be feared. Sojo goes on to talk about fear and lack of knowledge related to screening for cancer. She stated:

> "Yeah, because I didn't know that ladies had mammograms…There's lots of different information…And so it [Pap smear] was not a good experience. It was fearful. It was not comfortable. And I think now

> young ladies don't think anything about that…But it's not a fear that keeps you away".

Over the life course, because of access to information, fear has subsided.

Rose related the change in her personal view of cancer as directly related to her work, a transition from losing her previous job in banking to one in the health field as an administration assistant. Although her job is not clinically related, the exposure to the health field had made a difference in her perception of cancer. Rose stated:

> "The biggest difference is that I'm working at the [health facility]. That's the biggest difference…So then I try-- I want to get involved in things, you know, like the breast screening, those things that pertain to women, you know, first and foremost…So I want to just kind of move that from where I'm at today or where I was yesterday and move that into where I'm at today and be able to be an instrument for my family to say, hey, you know what? I may not know all of the answers, but, you know, this is what I've experienced and this is what I've heard."

As a result of the new position, discussions about cancer and screening have become "more open".

Hayley described that over the life course, the discussion has become more open, stating:

> "I think we're more open now about it 'n back then you--we didn't know much about it and it was, you know, just a scary, scary thing and no one talked about it much, where nowadays it's just <laughs>, you know, every time you turn around someone's getting some kind of cancer."

While not specifically addressing cancer screening, Hayley described that across the life course, individuals experience cancer as an event.

Bambi described access to information as the single factor that has changed discussions of cancer over the life course. Bambi stated:

> "Information, I don't think that my parents had the information, uhm... I have the information, my children has the information, regardless whether it came from me or it came from, you know, a class at school or it came from some research they had to do <coughs>, I just think there's more information available now and I think it's more public, and I think that's what's made the whole difference between my family and when I was a child, was the information that's available. "

Bambi also described her personal discomfort in discussing screening with her husband, yet open discussions with her female relatives, a change related to her transition from daughter to daughter and mother. She stated:

> "I still, you know, I don't discuss it necessarily with my husband but I discuss it with my mother, and I discuss it with my-my children, it's just uh... an uncomfort level, I guess I don't know if it's because I'm emotionally uhm... attached or there's an emotional involvement that would be difficult uh... would be an emotional issue if I discussed it with [husband], where it's not so emotional with my mother, you know, where if I discussed it with [husband] maybe I just don't want that emotional."

In this passage, Bambi described an inability in her marital dyad to discuss feminine issues, but a change over the life course in her ability to talk with her mother.

Cissie described the change in relationship to the feminist movement and transitions she experienced over the life course that she felt no longer existed among the younger generation. Cissie stated:

> "They didn't know. They didn't know. So this is -- so it's so disheartening to see how much our generation and the women around our age, a little older who really started that second wave of feminism that started in the '60s and the '70s and made us partners in our own health- in our own health regiment or whatever. It's really disheartening to see that it looks like the next generation has just lost, you know, lost that momentum so much."

Cissie went on to describe screening in the academic manner learned from her family of origin. Cissie stated:

> "I think it's much more just another list of the things that you need to be doing to- to keep your -- to keep your health in check or to- to make sure that uh... you know nothing is happening that you're not aware of. And so it's just on that list of things that you should go through. I'm trying to think of some other -- you know, most of the- the -- like yearly or whatever things that we go through, it's mostly geared around cancer…"

This passage illustrated a matter of fact approach to the screening process that has transcended the course of time in Cissie's family.

Like others, Yvonne described the change related to access to knowledge. Yvonne stated:

> "Well I think we, just as a general society, we know more about it and uhm... I don't have any problems discussing it when it comes up. It's just a-- just a part of life."

Yvonne described the change she noted in relationship to providers. Yvonne goes on to say that in her current family:

> "Um hmm. Oh, yeah. Uhm... much more open about, you know, you need to do this and, you know, and- and again I think that's kind of physician prompted. You know, the hemostat things that we do, and to the physical and all of that kind of thing. We- we my parents never did that kind of thing."

Yvonne acknowledged awareness that over the life course, openness about breast cancer screening has influenced participation.

In response to Research Question Five, women described transitions across time from their family of origin as daughters, where cancer was never discussed, to their current family where discussions of cancer are more open. Some identify specific events like a family member who has cancer or changes in work as factors that have influenced their awareness and participation in screening. Most have talked about societal transitions in terms of access to information about cancer as having the greatest influence in their current experience. Thematically, a change that has occurred over the life course relates to messaging and appropriate topics of discussion. Individual responsibility persists, but the practice of selective health messaging present in the family of origin does not persist in the current family.

Objective Three

Research Question Six: "What factors described by women in their decision to participate (or not) in breast cancer screening can be described as culturally specific attributes?" The responses to this question focus on particular attributes of culture rather than the broader cultural considerations previously discussed in terms of learned behaviors, values and beliefs related to health with implications for breast cancer screening. The examples illustrate collective cognition and norms as described in Appendix D.

To understand specifics the respondents were asked the question "Suppose you could use one word to describe yourself. What word would you choose?" And, "How does that word describe you?" The ecomap (Appendix B) content and relationships are presented in Appendix E. The depictions of these relationships lend support for the manner in which respondents described themselves.

Kim summed up her self-perception with:

> "Uhm... I would have to say happy…Uhm... well sometimes being the happy one isn't uhm... people don't understand sometimes just how can you go there? This project is so bad, and how can you go there and be so happy with it? And I think it's because you

> look down the road to what can be. So I try to weed out all the negative things and just try to focus on something positive. And sometimes I get kind of stiffed with it, 'cause I don't think taking my happiness for a weakness or something, or don't really think I'm really serious, but uhm... that has sometimes come back to kind of bite me, 'cause they think I'm so happy and bubbly that I couldn't possibly know what was really going on."
>
> Kim

Kim's ecomap identified a good relationship with her employers (Appendix E), but a close relationship with her co-workers and peers. These comments indicate a collective expression of attitude and cognitions (Appendix D). Coffy described herself in the following way:

> "One word. Faith…My- my faith has sustained me through life, but it's also ve- very active. Uhm... It- it's sustained me through uhm... oh God, traumas and- and uhm... probably something else you didn't know either, I uhm... After undergrad, I- I got married a year later, and in my- during my marriage we had three children…"

The quotation goes on to talk about the deaths of her three children. The church was identified as a good relationship by Coffy and friends, who are part of her church circle, as close relationships (Appendix E). This quote also illustrated a collective expression of values (Appendix D). Maya beamed when she described herself in the following way:

> "I think Maya would choose phenomenal…Phenomenal means that I am able to use that visionary that I see that is so far fetched, not knowing how I'm gonna get

> there, but in some ways seeing that there is that goal or it is that vision, and rattling those persons that's necessary to get me to that goal. It may not be me, but it'll get there. <laughs>"

Maya surrounds herself with good or close relationships, as indicated from her ecomap, from friends to family and to work (Appendix E). This quote illustrates a collective expression of identity and emotion (Appendix D). Maya described in other discussions her close identification with her sorority and the Black Nurses Association.

Sojo smiled with delight when she described herself in the following way:

> "I got to go you know, I never even looked this word up but I'm sure it's me, eclectic…It's a holistic word for me because I was raised to accept or experience a lot of things, not the downside of life certainly, but taste this food. This is caviar, because my parents were caterers. Drink this tea. Miss Fuller [ph?], Dr. Fuller's wife said it came from England especially, and smell it. It's in a canister. Listen to this music. Peter Fuller plays bagpipes, so I was raised around a lot of things and totally taught to experiment and not to just be discouraged about differences in people or sounds of music or books, you know, music. When I was a little kid, my favorite was "Peter and the Wolf" and if you ever read it, if you ever heard it, I mean. I heard it the first time I heard it and along with that gift I received, oh what's the guy that George Gershwin, is it the Gershwins?"

Sojo's ecomap depicts "eclectic" relationships ranging from close (family, household members) (Appendix E) to conflictual (church, co-workers) (Appendix E). Sojo went on to describe her lack of tolerance for those viewed as "using the system". She clearly indicates individual expressions of cultural attributes (Appendix D) in her values and social behaviors.

Rose described herself in the following way:

> "Servant…The way that I've began to look at life, and how it all relates to what we do in life, you know I just look at myself more as a servant type of person, a person who wants to help, a person that, you know, wanting to fit in wherever, you know, they could be of assistance. So, that's why, you know I look at myself as that type of a person, one that's helping."

Rose depicted close relationships with her family members, in particular her daughter and mother (Appendix E). While the relationship with her mother was strained as a child, it has developed into a close and valued interaction. Collective expressions are evident in motivations, attitudes, roles, and values (Appendix D). While I thought of the use of the word servant to be pejorative, her explanation described a commitment to her family.

Amy struggled when describing herself:

> "I guess the one that keeps coming to mind is one that isn't uhm... very flattering but it's uh... under-confident, because I feel that that's, you know, something that I have to work hard to get over. So I would say I'm-I'm under-confident…Well uhm... as I've been more involved in the community and, you know, lived my, well, seventeen years here in [city] one of the things I feel under-confident about is uhm... my lack of education, that I don't have a college degree, that-that bothers me. Uhm... I'm getting better about different things being in groups of people and

> speaking and, you know, socializing and different things like that, but I think that-that's a big one with me, that I feel uhm... under-confident because I didn't go on to get a higher education."

Amy's depiction of relationships is reflected in her ecomap as a close relationship with her father and a conflicted relationship with her mother (Appendix E). While having close relationships with her household members, the "under-confidence" relates directly to her decision to become pregnant and marry directly out of high school rather than going to college. These comments are examples of individual expressions of identity and emotion, as well as responsibility (Appendix D).

Hayley's affect was flat, with little facial expression and a flat tone of voice, when she described herself in the following way:

> "I'm probably pretty reliable, I guess, and I always do what I say I'm gonna do, and I'm a pretty kind person…Uhm... Pretty well I guess just through my job. I'm pretty loyal and uhm... always there, always on time, never miss a day. I guess maybe I don't know if <laughs> that's good or bad. And uhm... I don't know, I just have a lot of friends and so -"
>
> Hayley

These comments are reflected in her ecomap, describing her employers and friends as close relationships (Appendix E), which are examples of collective expressions of attitudes (Appendix D).

Bambi laughed and chuckled as she described herself as:

"Cheerful"

And went on to explain the rational for her choice:

> "Well most of the time I try to always find the positive in any situation, you know, whether it be at work, personal, home, I-I just-I'd rather be positive and happy than negative and angry…I think it has because I don't-I try not to hang onto anger, and I've seen people that do and it makes 'em very unhappy, very cranky, unhealthy people, I see that in everyday life, you know, people just have a negative at about-attitude about everything or anything, and you really can't-even when you say "Oh it's not that bad", "Oh you don't know", you know, I-I really don't like to talkin' to people or being around people like that. So I, several years ago, decided, 'cause my Mom's kinda like that, I don't wanna be like that, so I consciously tried to make that change because it's better for me physically, emotionally, it's just better for me."
>
> Bambi

These comments are reflected in Bambi's ecomap description. She describes no relationship with a church, distant relationships with friends, neighbors, and health care providers (Appendix E), conflictual relationships with siblings and other family and members (Appendix E) and, a stressful relationship with her co-workers and peers (Appendix E). Bambi also described in previous comments the conflicted nature of her family of origin. These comments are illustrative of an individual expression of motivation (Appendix D).

Cissie's response was interesting and the most descriptive and introspective of all. She described herself as:

> "Multi-faceted…I have many different ways of looking at the world. I look at the world in artistic ways. I also look at the world in very practical ways. It's kind of- I'm a right-brain person and a left-brain person. I can't say that I'm balanced, but I try to keep some kind of a balance, and my nature- my dual nature tends to balance those out. Because if I get too right brain and flaky, then my other side takes over and starts imposing order on that. And if I get too orderly, then my free-floating side starts to say, "It's time to lighten up and not take this so seriously, or whatever." So, I think that dual nature tends to keep me balanced, so I have lots of different interests. I love theater, arts, music, some science, history. There are some things about math that I really love. In terms of academic kind of stuff, or even pleasurable stuff, but I just have a lot of varied interests, and I enjoy learning about everything, and having those connections take you someplace else to learn about something else. And more connections take you, and eventually you find somebody who has been involved in learning about somebody else."
>
> Cissie

Most of the relationships depicted on Cissie's ecomap are close or good, with the exception of a stressful relationship with her mother due to long distance caregiving (Appendix E). The comments in this quotation and further discussions related to Marxism and communism are a combined reflection of collective expressions of social behavior and values with individual expressions of values also (Appendix D).

Yvonne described herself in the following way:

> "Hmm. One word. Uhm... vibrant…<Laughs>. Well I just feel like I- I just love life. I love everything. I love-- like I said, I love learning,

> uhm... and I feel very alive and very invested in my life and the life of the people around me."
>
> Yvonne

Yvonne's ecomap identified close and good relationships with the exception of co-workers and peers (unrelated to who she identified as colleagues) (Appendix E). Her educational background is music and theater, and she travels extensively with her husband, offering support for her self-description as "vibrant". The cultural attributes most closely reflected in this description are an individualistic expression of values (Appendix D).

In response to Research Question Six, most of the respondents expressed collective attributes in describing themselves supported by their ecomap depictions of relationships. However, the overall descriptions provided to Research Question Five depict the individual cultural belief systems present in the United States. For example, expressions of personal responsibility for health and breast cancer screening are individual expressions of self-perception. That is, each individual woman interviewed described themselves as responsible for their health or decision making related to the use of screening services while each described themselves as members of families. Their self-perception was not based on the relationships of those around them. Cognitively, each described a focus on personal needs reflective of an individual expression rather than making their health decisions based on the needs of the family first. Motivation for participation in breast cancer screening and other health related activities indicated individual expressions, with most women identifying their individual need for the use of services. Therefore, while women describe and depict relationships supportive of their decisions in a collective sense, the actions described by women in their decision making related to the use of health services and cancer screening reflected individual expressions of cultural attributes (Appendix D).

It should be noted that the concepts of culturally specific attributes in terms of collectivism versus individualism were most evident in the responses of women and their family relationships. Rather than finding ethnic or racial differences, the women were similar in their expressions. This disputes the stereotype that White and African American women are different and that African American's are "more collective" than Whites based on their heritage. Instead, the findings suggest risks with over generalization and stereotyping based on a false dichotomy.

Summary of Findings

This chapter presented the major findings from interviews of ten African American and White women between the ages of 40 to 51, who have middle incomes, and access to health insurance. The data revealed that health beliefs and values as learned behaviors in the family of origin translate into similar health beliefs and values in the current families for all women. Increased access to information has transformed the messages to factually based accounts for all women. In all cases, cancer as a topic of discussion was inappropriate within the family of origin. Most of the women described the topic as taboo and their understanding of cancer in the family of origin as unclear. Most also indicated that they felt their families did not know enough about cancer to discuss the disease.

All women described their mothers as guardians of family health. This role-related belief persists within the current family, even though some women describe their husband's involvement in health related decision-making.

In terms of breast health, women described a form of selective health messaging in their family of origin. That is, mothers in the family of origin openly discussed strategies related to general health, but selected messages for breast health unrelated to cancer. Largely, breast discussions were vague and frequently in the context of sexual behavior.

Across the life course, increased access to knowledge seems to have made the biggest difference in the messages women impart with their daughters about breast cancer screening and that influences their personal decision making. Few women directly described family relationships as important factors in their decision to participate in breast cancer screening. Some mentioned access to the services, insurance, and physicians as positive influences.

Health access in the family of origin, on the surface, was similar among all respondents regardless of racial/ethnic identity. However, among several of the women, the access was directly related to their mother's employment, which afforded them special privileges. While all women had access to providers, the mechanism allowing that access was different for African American women than White women. All of the African American women described their mothers as employed (service based), and all of the White women described their mothers as homemakers who had access to insurance through their spouse or could afford to pay for services.

Responses revealed cultural beliefs in terms of learned behaviors, communication and decision-making.

Overall, these reflect the individualistic nature of the culture of the United States. However, when examining the particulars of personal descriptions and ecomaps, women portrayed collective attributes, indicative of the socialization of women as family caregivers. Unlike the stereotypic expectations that African American women are "more" collective than White women are, all the women in this study portrayed collective characteristics.

Chapter 5 will provide discussion of the findings in relation to each of the research questions, limitations of the study, and implications for future research.

Chapter 5

DISCUSSION

Overview

The purpose of this study was to explore family ecosystem and life course factors associated with women's participation in breast cancer screening. The exploration was accomplished through interviewing ten women between the ages of 40 and 51 years, five of whom were African American and five who were White. Ecomaps also were used to determine relationships viewed by the women as strong and supportive. Responses provided support for the theoretical foundation of this study and led to an understanding of the influence of learned health behaviors on decision-making and breast cancer screening. Discussion of the findings is presented in three sections. The first section addresses the theoretical foundation and changes to the conceptual model based on the findings, the second section examines the themes in the findings, and the third section explores limitations and recommendations for further research.

Theoretical Foundations

Two theories served as the foundation for this research. These theories included the family ecosystem theory by Bubolz & Sontag (1993) and the life course theory by Bengston & Allen (1993) and Price, et al., (2000). This study supported Bubolz & Sontag (1993) family ecosystem perspective of the social/cultural environment in relationship to values and beliefs about health and learned behaviors. The family ecosystem theory (Bubolz & Sontag, 1993) describes the social/cultural environment as the location of cultural constructions in the form of norms, cultural values and patterns of behavior. Values of a culture become evident in the choices made in the pursuit of a goal (Sowell, 1994). Health was evident as a value among all the participants. Learned health behaviors were evident in the descriptions women gave about their families of origin and the messages about health relayed to them by their mothers. These learned behaviors were transmitted to their own families in health messaging. While the content of the messages changed over time as a result of improvements in the human technology environment (increased access to information and improved technological advances), health messages learned in the family of origin were transmitted to the current family.

Most of the women in the study spoke of the family (the environed unit) in terms of their immediate family consisting of spouses and children, with parents (mothers) as extended family members. Several of the women who were not married at the time of the interview described their mothers as part of their immediate family. Ecomap descriptions demonstrated the strengths or weaknesses of the relationships women viewed as most important in support of their environed unit and their social/cultural environment.

The human built/technological environment, described as access to health care services, is an important consideration within the families of origin of the participants in this study. All women described having access to health care services. All were raised in urban or suburban communities, increasing the availability of health care resources. This relationship may have contributed to the use of health care services by women both in the families of origin and current families.

The life course theory as described by Bengston & Allen (1993) and expanded by Price, et al., (2000) asserts that the individual, as a member of a family or social unit, changes over time. As a result, temporal dimensions, social contexts, development, diversity and aging influence the individual across the life course. The health messages women received within their families of origin changed over time in terms of the topics viewed as appropriate. Temporal influences related to history include the manner in which breasts were discussed. Either there was no discussion or the topic was discussed in relationship to sexual activity. Some of the African American women discussed their perception of the learned health behaviors within the context of the 1950's and the 1960's and the socialization of children regarding racism. Health messages involving nutrition were consistent across the life span. Less consistent were messages about dental health, cleanliness and rest.

Learned behaviors about health consistently appeared as evidence of culture within this study. Data collected in the interviews and the ecomaps were used to identify particular cultural attributes of these women. Triandis (1995) noted that culture is responsible for "different levels of social support and also for different kinds of interpretations of life events." The responses were examined for cultural attributes and to explore the expression of culture through behaviors as suggested by Sowell (1994) rather than to measure cultural differences between the respondents. Each of the women identified learning health behaviors within their families of origin. The behaviors specific to nutrition continue to be used in the current families. Most of the women learned about breast health as adults and have adapted their health messages within their current families to include breast health information. As described by Lytle, et al. (1999) families of origin did not prioritize prevention messages related to breast health. Instead families avoided the breast as a topic of conversation or presented it in terms of sexual development. Consistent with the Lytle study, African American women spoke in greater detail about nutrition than the White participants.

Across the life course, decision making related to health within families of origin and current families remained a role of women. Denham (1999a) described mothers as responsible for family health. Gendered roles for women across time include those specific to caregiving (Baca Zinn & Eitzen, 2002). Within this study, mothers facilitated the health-related decision making for their children, wives for their husbands, women for themselves, and daughters with their mothers.

Decisions for participation in breast cancer screening were made personally, based on values about health and beliefs about the appropriateness of screening. These decisions were made after recommendations from providers or from information reviewed by the women. As described by Plager (1999) family legacy contributed to the decision-making processes used by these women. Each of the mothers in the families of origin participated in activities that contributed to the development of family meanings about health concerns. Each of the respondents acted upon these meanings that resulted in specific practices focused on promoting individual health behaviors (Plager, 1999).

Life course transitions and events were less evident as influential for women in decisions about breast cancer screening. While many of the women had experienced the divorce of their parents or personal divorce, none identified divorce as the reason they did or did not participate in screening. Several women did identify access to insurance resulting from their own employment as influential in their decision to participate.

Figure 2 (first presented in Chapter 1) depicts the factors conceptualized as influencing the decision to participate in breast cancer screening. Figure 4 presents a revised conceptual map reflecting changes. In Figure 2, the factors influencing the decision to participate in breast cancer screening were represented as solid or broken lines linked to the decision. Those within the shaded area were considered as factors within a cultural context influencing a decision. Factors outside of the shaded area represented factors thought to be irrelevant for this study and eliminated in the sample selection process. Race was highlighted because only African American and White women were interviewed. Changes to the model (Figure 4) were made to clarify the conceptualization based on the findings.

In Figure 4, health related behavior represents the social and cultural expectations for a health behavior. The behavior is linked directly to the person who develops an awareness of need for a particular behavior. This awareness is then filtered through the cultural context of the individual as a member of an environed unit with beliefs, values and health knowledge. Other factors that may or may not influence the decision to participate include insurance, education, income, race, and the life course. Taken together, these factors influence the actual decision-making related to breast cancer screening (Figure 3 in Chapter 1). The decision making process includes the value of health, a recognition of need, a standard set for annual screening and the goal of obtaining the screening. As an outcome, women chose to participate in appropriate screening services. For example, within this study each respondent identified the value of health, each recognized the need to have a mammogram starting at age forty, each acknowledged the standard for having an annual mammogram, and each identified the goal that they would have a mammogram. Only one of the participants acknowledged that they procrastinated when it came time to actually participate in the screening.

As the recommendations for screening are considered, in terms of personal responsibility for health within the context of the environed unit (Bubolz & Sontag, 1993) the individual makes a decision to use or not use, breast cancer screening. The meaning of health within the family as part of family legacy is demonstrated in the personal behavior (Plager, 1999) to act on recommendations for screening. Figure 3 in Chapter 1 represents the decision making process of breast cancer screening which remains unchanged and is ultimately reflected in the use of services. For example, each of the women valued screening, recognized the need, and acknowledged the standard and either participated or planned to participate in screening.

The changes in the model reflect the greater influence of the development of learned health behaviors within the family of origin and their use in the current family. Family communication and the development of learned behaviors occur through the exchange of messages (Fitzpatrick, & Ritchie, 1993). The interactive process of communication within the family (Bubolz & Sontag, 1993) is an important consideration in the development of learned

Figure 2. Conceptual Framework: Factors Influencing Decision Making (Chapter 1).

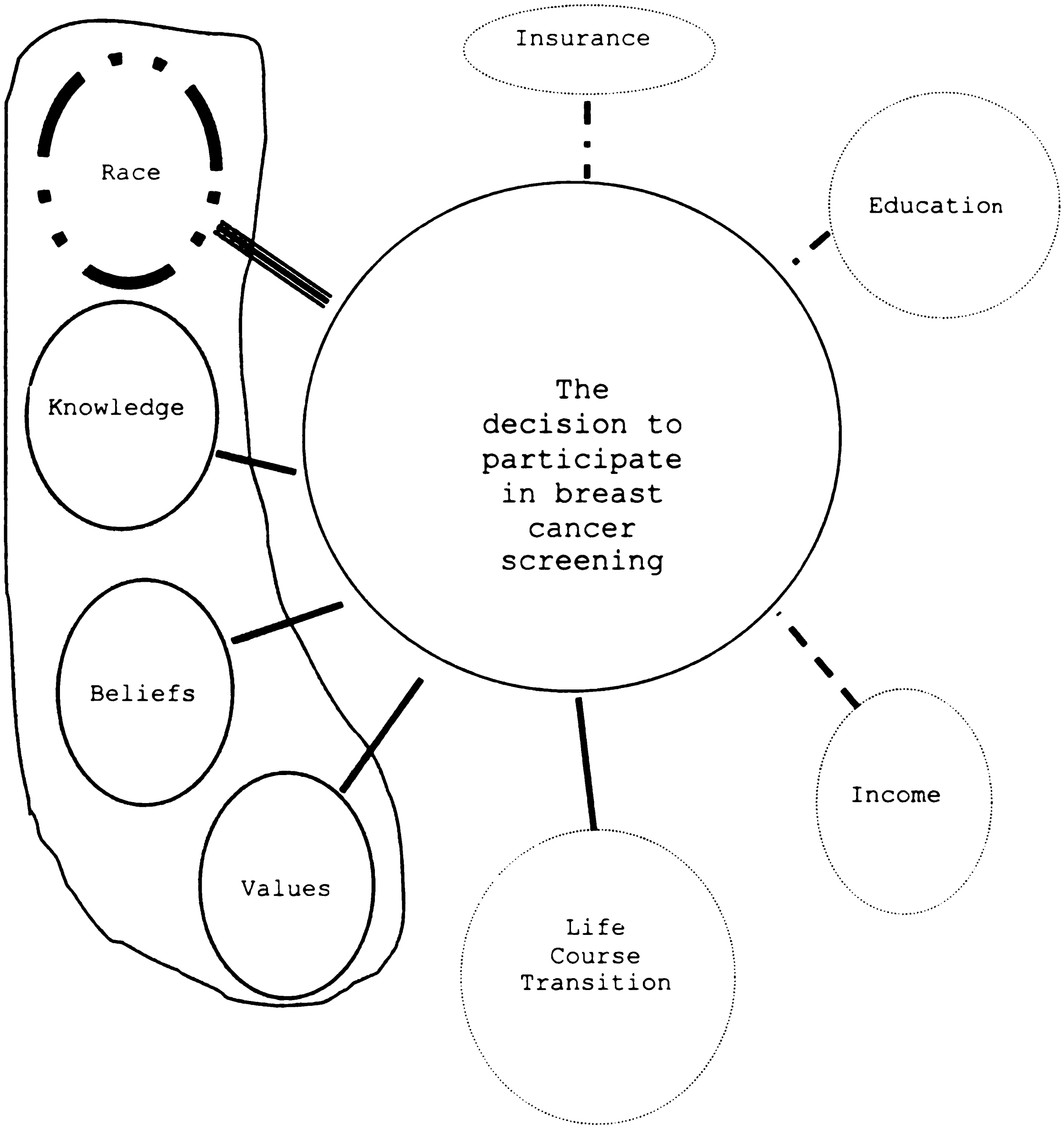
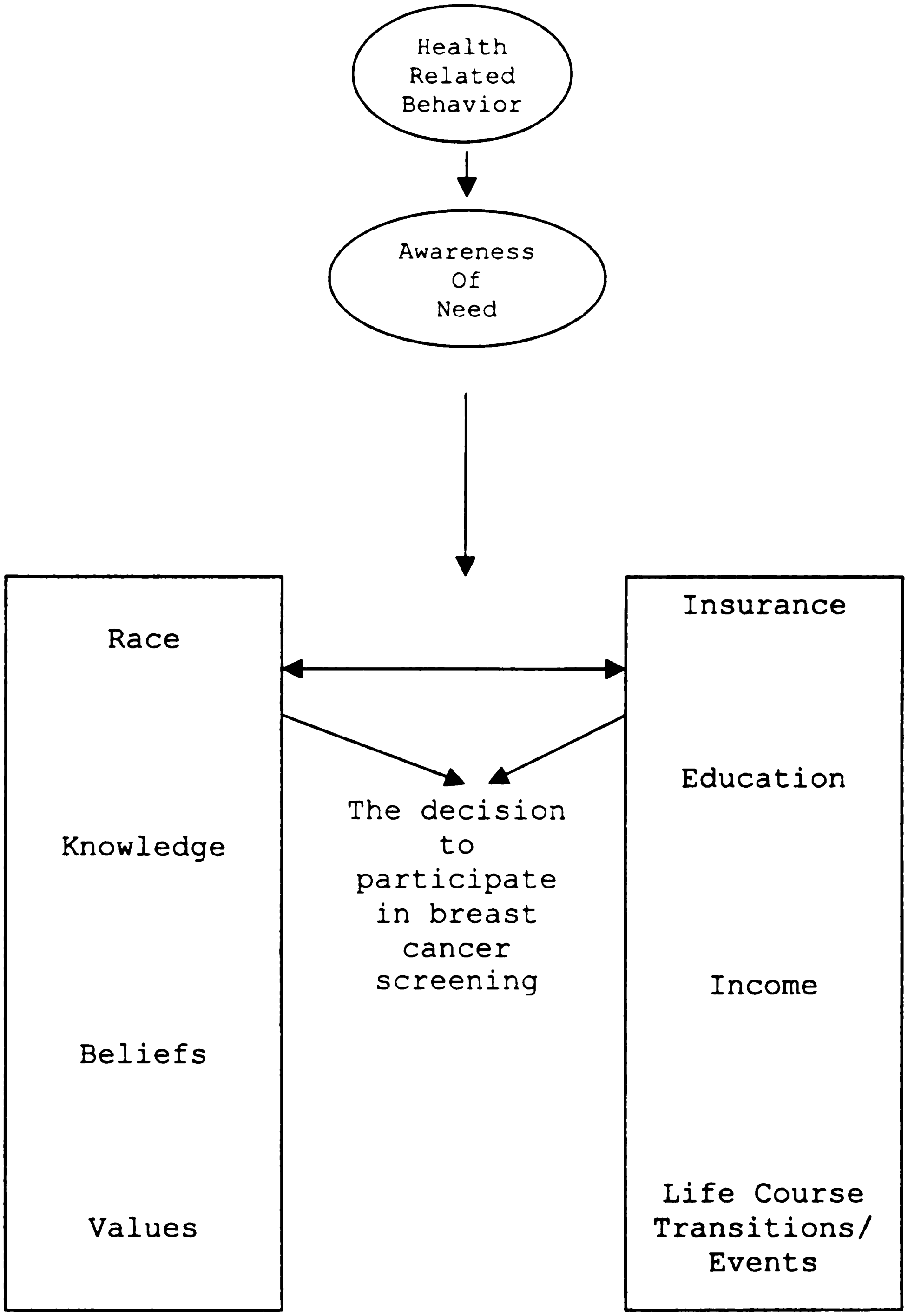


Figure 4. Revised Conceptual Framework: Factors Influencing Decision Making



health behaviors and is influenced by the encouragement of the family of origin to express or to censor specific topics (Ng, et al., 2000). As a result, each of the participants learned the value of health within the family of origin and translated the meaning of these health behaviors into prevention related activities.

The next section presents the key findings. The respondents in this study provided examples of how the health belief systems within their families of origins formed their current belief systems and patterns of behavior.

Key Findings

Analysis of the data revealed five themes as factors contributing to the use of health care services and breast cancer screening. Learned health behaviors, knowledge dissemination, selective health messaging, access to services, and personal responsibility were consistently identified throughout the interview data. The dynamic nature of the individual within the life course, as described in Chapter 2, influences decision-making processes. The five themes that emerged describe the health values, belief systems, and decision making of the women participating in this study. Table 3 provides a description of the relationship between the research questions and the coding used to analyze the data with the key findings. Each of the themes supports the six research questions.

Theme One: The Influence of Learned Health Behaviors

The influence of learned health behaviors on the respondents is presented first because learned behavior influences all other themes. Learned health behaviors (Denham, 1999a) within the family of origin either directly or indirectly affect women's decision making related to their personal family health across the life course. This knowledge has implications for breast cancer screening participation.

Women have been responsible for family health across the life course. As described by Denham (1999a), health-related practices are affected by social and cultural contexts, but are learned through family health routines. Each of the informants discussed similarities in the manner of incorporation of health knowledge within daily practices especially related to nutrition. As in the Denham (1999a), study families of origin played important roles in shaping health beliefs and practices. These learned behaviors related to health were influenced by social contexts including pamphlets, brochures and social support systems

Table 3

Research Questions Linked with Codes and Key Findings

Research Question	**Coding Scheme**	**Theme**
1. How do women describe their health needs in relation to their family?	FOH-family of origin health FOH- family of origin health discussions FORHD- family of origin relationships health decisions FOHB- family of origin health beliefs	1. Learned health behaviors 3. Selective health messaging. 5. Personal responsibility
2. Where do women learn about their breast health needs?	FOBC-family of origin breast cancer FOBCD-family of origin breast health discussions	3.Selective health messaging 5. Personal responsibility
3. What are the effects of life course transitions and events experienced by women on their participation in breast cancer screening?	LCTFOA-life course transition family of origin LCTCF-life course transition current family FoCfBCD-Family of origin current family breast cancer decisions	1. Learned health behaviors 2. Knowledge dissemination 4. Access to services
4. What family related factors do women consider when making the decision to participate or not in breast cancer screening?	CFH-current family health CFBC-current family breast cancer	2. Knowledge dissemination 4. Access to services
5. How do women perceive their family relationships, life course transitions and events as influential in their decision to participate in breast cancer screening?	CFH-current family health CFHD-current family health discussions FORHD-family of origin relationships health decisions FORBCD-family of origin relationships breast cancer decisions CFRHD-current family relationships health decisions CRFBCD-family of origin current family breast cancer decisions	2. Knowledge dissemination 3.Selective health messaging. 5. Personal responsibility
6. What factors described by women in their decision to participate (or not) in breast cancer screening can be described as culturally specific attributes?	FOHB-family of origin health beliefs FOBCB-family of origin breast cancer beliefs CFHB-Current family health beliefs CFBCB-Current family breast cancer beliefs	1. Learned health behaviors 3. Selective health messaging. 5. Personal responsibility

of other women. For example, respondents discussed receiving information from providers, health insurers, and on television and radio and with women friends and relatives.

Goodman (2001) suggested exploring conditions of life that affect health rather than racial differences and the use of race as a proxy for variations in health. Goodman described the underlying reasons for health differences that often go ignored in terms of access to medical care and diet. These reasons were not evident among the respondents, either within their families of origin or their current families.

Bubolz and Sontag (1993) family ecosystem theory depicts the interactive processes between families and their surrounding environment. The adequacy of the environment in providing opportunities to meet the needs and values of the family is part of the interaction. All of the participants described similar patterns of learned behaviors related to the use of health services, especially during times of illness or injury. Only a few of the women described learning prevention behaviors (immunizations or dental health) in conjunction with the health care system.

The participants demonstrated the role of family legacy (Plager, 1999) in their development of meaning about family health concerns. Families then put the meanings into practices, habits, and activities. Across the life course, nutrition has remained connected to descriptions of health, and each respondent described how this information was used as learned behaviors within their current families. Women as arbiters of health within the family have remained constant across the life course. Learned health behaviors, as part of the cultural context, influence the manner in which women describe their health needs within the family.

Theme Two: The Influence of Knowledge Dissemination

The dissemination of knowledge across the life course has changed from families having limited knowledge about cancer to the availability to knowledge in a variety of forms. As a result, increased knowledge has affected the decision making of each respondent and the use of breast cancer screening services. The influence of knowledge dissemination is closely related to learned health behaviors. Because health behaviors are developed, maintained and changed within the family setting (Campbell, 2000) each respondent learned about behaviors to remain healthy. As knowledge improved, each woman described a translation of this knowledge into prevention related behaviors. This translation occurred most often in conjunction with recommendations from health care providers, personal experience with cancer or through conversation with other women.

Women's roles included teaching and modeling healthy behaviors within the families of these respondents as described by Denham (1999b). Women's role responsibility for family health (Denham, 1999a) has changed little over the course of time. While some of the respondents spoke of male family members participating in the health decision-making process, each respondent ultimately decided upon the knowledge that would be disseminated within the family. Respondents described decisions to include health knowledge as based on having more access to information from physicians, insurance companies, and through their children's school systems. Bubolz and Sontag (1993) family ecosystem theory supports the interactive nature of these social and cultural environments as a contextual backdrop for dissemination of knowledge. The application of the life course and family ecosystem theory to dissemination of knowledge would explain the respondents' descriptions of ways in which discussions of health and cancer have changed from their family of origin to their current family experience.

Theme Three: The Influence of Selective Health Messaging

Selective health messaging is presented separately. Selective health messaging relates to the specificity of the health message women received within their families of origin and conveyed to their current families rather than knowledge.

The interviews revealed that health behaviors were learned within the family from women, and that overtime, these health behaviors were adapted and altered to fit the need of the family based on the current knowledge available. As described by Misra & Aguillon (2001), childhood is the time when health behaviors and lifestyle patterns are established, and these behaviors persist throughout adulthood. Each of the respondents described behaviors they learned in childhood (nutrition) and how they used the same messages within their current families.

Parents represent one of the most influential groups in the acquisition of health promotion behaviors such as eating behaviors and smoking (Misra & Aguillon, 2001). As depicted within the ecomaps, women identified strong family and support systems used or considered in their decision-making processes. Women frequently identified their mothers as the messenger of health within the family of origin. However, the health messages relayed to the respondents by their mothers were selected according to the appropriateness of a topic (breasts) or the amount of knowledge related to a disease (like cancer). As described by Lytle, et al., (1999), the selection of topics may be related to the low priority the families placed on the topic or general avoidance of the topic. Overtime, respondents identified that peer groups (female friends and siblings) participated in health discussions to a greater extent than with their mothers. The phrase "selective health messaging" is used to describe the manner in which women learned about health behaviors.

Communication was not recognized in the beginning of this study as one of the key components of consideration. However, communication is one of the most significant interactive processes within the family ecosystem (Bubolz & Sontag, 1993), and involves the use of a variety of techniques to transmit information. Within the families of these respondents, the content of health messages and openness of discussions has changed over the life course relative to the appropriateness of certain topics. Huang (as cited in Kelly, et al., 2002) states, "Family communication patterns and styles influence children's attitudes and behaviors". So, while little is known about the influence of families on health behaviors [of adolescents] (Lytle, et al., 1999), the types and content of messages transferred from parent to child lend meaning to specific topics, such as cancer. Because of this awareness of the value of communication within the family in relationship to health messages, a review of communication within the family was added to the literature review.

One way that culture is reflected within a group is through language (Sowell, 1994). Among the African American women in this study, some of their families of origin used adages to convey health messages. Adages have been used to impart health messages. For example Abraham Lincoln referred to alcohol as "intoxicating liquor" while addressing a temperance society in 1842 (Klatsky, 2003). While the conservative society at that time disapproved the reference to alcohol, recent research has demonstrated the benefit of "reasonable" alcohol intake and the development of coronary artery disease (Klatsky, 2003). Adages such as "a picture is worth a thousand words" have been used to describe the mentoring necessary to inspire students toward a lifetime of physical activity (Butler & Anderson, 2002).

Content and language used to describe a topic create meaning. Language and meaning in everyday life is identified as a core assumption of ethnomethodology

(Gubrium & Holstein, 1983). From an ethnomethodological perspective, the real world of things is constituted by "language in interaction" (Gubrium & Holstein, 1983, p. 655), producing social organization within the family and assigning meaning to social conditions.

Cancer, within the families of origin of these respondents, was not discussed. Most of the women described their families as having little knowledge about cancer and as a result, the topic was seldom discussed. Respondents noted a change in their perception of cancer that has changed over time with increased knowledge. Most of the respondents learned to fear cancer due to the lack of discussion of cancer within their families of origin. Each described a change in the meaning of cancer as a result of increased knowledge and appropriateness of cancer as a topic of discussion.

All respondents described the lack of attention paid to the dissemination of breast health information within their families of origin. While several women said that breasts were simply not discussed, others remembered the breast health information they did receive in direct relationship to the sexual nature of breasts and avoidance behavior. Several women also noted that over time, discussions about the breast have become an appropriate topic with their mothers as they share breast cancer screening concerns.

Intricately woven within the selective health-messaging theme is the influence of learned behaviors and knowledge dissemination. Over the life course, these women learned about health behaviors and learned that the breast is sexually connected. With increased knowledge over time, these women have transferred the idea of health to breast health and have made decisions related to their personal breast health based on a change in these learned behaviors. The women have also adapted the new information about breast health to their family discussions and the transmission of learned health behaviors.

Some of the greatest increases in the incidence of breast cancer over the past forty years have occurred at times when celebrities acknowledged their breast cancer (Corbett & Mori, 1999) and the news media has informed the public about the disease. It is within this same forty-year time frame that women in this study noticed a change in the way that breast cancer was discussed in their families of origin and their current families. The selective health messaging process appears to coincide with increased knowledge that leads to a change in the belief system.

Theme Four: The Influence of Access to Services

Access to services in terms of transportation, insurance, and education has been addressed throughout this study. The African American women in this study provided a unique view of access within their families of origin that may have changed over time in direct relationship to their employment.

As described earlier, women of color traditionally receive the lowest wages, perform the worst jobs, or are unemployed (Baca Zinn & Dill, 1994). Historical factors associated with the economic strains experienced by white women include low work force participation, less work experience, and less education (White and African American women) than males. These issues contribute to fewer resources for women in terms of social security, pension accounts and personal savings and less access to the best health insurance. The work of African American women changed over the course of time in response to historical changes. As described by Schneider in her review of the book, "Maid in the U.S.A." (1998), African American women entered domestic service first in Southern cities then North and Midwest metropolitan areas in response to two events. First, White immigrant women left the domestic arena for more lucrative jobs in the early twentieth century and during the Depression and World War II. From the 1960's on, African American women began to leave domestic service as social change brought about other labor market opportunities.

Some of the African American women in this study had mothers who worked as domestic servants and had access to health care directly as a result of their employment. While they did not have access to insurance, they did have access to health care from their employers, and this carried over to the family members and friends of the women employed as servants. The respondents in this study shared distinct memories of having access to health care as a result of their mother's work. Access to health care is dependent upon health insurance. Access to health insurance occurs through participation in the labor market directly through one's own employment or indirectly through spousal employment.

While the socioeconomic status has changed over the course of time for these women, the health values have remained the same (Bubolz & Sontag, 1993). However, interaction with the health care system (the social and cultural environment) has become dependent upon the availability of insurance and income. The African American respondents had access to health care through their mother's employment, but are now dependent upon access to health care through insurance. The informal system of access is no longer possible due to the formalized and regulated health care system. White respondents had access to health care related to their father's employment. As adults, the African American and White respondents had insurance through their own employment. One of the White women described a period of time when she worked but did not have insurance with a resultant loss of access to health and breast cancer screening.

Theme Five: The Influence of Personal Responsibility

The influence of personal responsibility for health care is evident throughout the respondents' descriptions. Implicit messages that the women needed to conduct themselves in certain ways to remain healthy were conveyed. Each of the women learned the value of health as part of their family ecosystem structure and adapted these learned behaviors within current health care practices.

Only one of the women interviewed spoke of her decision-making in direct relationship to her perception of quality of life and the needs of her family. All other women spoke of their decision to participate in breast cancer screening as a result of information they had received from physicians or because they "knew" the appropriateness of the screening test based on their age and need for early detection. The women in this study felt it important to participate in breast cancer screening for personal health. The culturally specific attribute this behavior describes is cognition, as an individual expression. Triandis (1995) defines the individual expression of cognition, as a "focus on personal needs and rights".

White women described the lack of discussions with their spouses related to health care, yet all of the women in this study described playing some part in the health decisions for the entire family. Roles for women as family health advocates have not changed over the life course, and family ecosystem processes (Bubolz & Sontag, 1993) reveal women as the decision makers for the family while taking personal responsibility for their own health needs.

Methodological Issues

While the semi-structured interview format guided the interview process, no two interviews were the same. Some respondents freely shared information and seemed to enjoy the process of discussing these topics, while other respondents provided limited answers, even with prompting. This prompting at times led the interviews astray or prevented a full response to the next question. While clarifications were sought, some of the respondents provided such limited answers that in depth prompting would have tainted the responses to the questions. The ecomaps provided some validation for the responses, especially among those respondents who described difficult relationships with their mothers in the family of origin. Those difficult relationships were depicted with the ecomaps.

The ordering of the questions changed after the first two interviews. The question asking for adages or sayings about cancer originally preceded a question about the meaning of cancer. The ordering of these two questions in subsequent interviews changed because it was more logical to ask questions about the meaning of cancer before asking about sayings and adages. A second issue involved a question that was ineffective in eliciting the desired response. The question is presented in Table 4 along with the intent of the question and how the respondents answered the question.

While the question did not elicit the response desired, it did not affect the overall research. Responses to other questions provided a sense of learned health behaviors within the family and how women made the decision to participate in breast cancer screening.

Table 4

Difficult Interview Question

Question	Question Intent	Question Response
In the decision to (or not to) participate in screening tell me the factors you considered.	What family related factors are taken into consideration when deciding to participate or not in breast cancer screening? Did the respondents consider their family needs first?	Whether they knew about breast cancer screening or whether their physicians had told them to have the screening.

Using an interview format and semi-structured questions facilitated the interview process by exploring the themes as they emerged rather than counting the numbers of individuals exhibiting a particular concept (Strauss & Corbin, 1998). The exploration of health and breast cancer screening beyond the limits of a structured questionnaire (and my perceptions of why women do or do not participate in breast cancer screening) was facilitated through the use of qualitative methodology. Throughout the interview process I was aware of my personal biases and beliefs about the use of breast cancer screening services. The findings indicate that it is important to understand the health beliefs of an individual within the cultural context of learned health behaviors before fully understanding the use of screening services.

Limitations

There are several limitations of this study. The sample involved in this study is not representative of all women age eligible for breast cancer screening and who have a higher level of education, income, and insurance. First, while there were both African American and White women involved in this study, there were only five of each represented. Second, the interviews were conducted with women who were known to the researcher, and as a result the responses may not have been as forthcoming as they may have been. Third, one of the women was a registered nurse, and two of the women worked in ancillary services within the health care system. Whether or not this changed their opinions about health and the use of services is unknown.

A fourth limitation involves barriers to health care. The respondents were not asked specific questions about their knowledge of income or insurance within their family of origin. This may have been helpful to fully understand their use of health care services within their family of origin.

The fifth limitation of this study is that it only focused on African American and White women without including other ethnic or racial communities. Therefore, it is not known how women from other cultures might respond.

Lastly, this study was conducted in a Midwest community among women who where raised and who currently live in urban or suburban centers. The differences in responses to these questions among women who live in large metropolitan or rural communities are unknown.

Recommendations for Future Research

This research was limited to questioning women who have access to health care services. There remains the question of how women who have limited resources or education would respond to the same questions.

This study did not determine baseline-screening knowledge. Future studies should collect quantitative baseline knowledge information along with the qualitative questions and compare the responses. This approach may be more useful in understanding the needs of women who are eligible for screening and the development of educational materials.

Broadening the study to include respondents from other geographic or regional locations and ethnic or cultural communities would add depth to understanding health and the use of screening services. Using an ecosystem approach within other groups of women could reveal how health beliefs and learned health behaviors are developed and disseminated.

This study included women who have health care providers who they know and have grown to trust. Further study regarding the use of health care systems with inconsistent health care providers may influence the use of services even among women who have insurance and income.

This study did not include women who lack insurance and have lower education but who have access to federally funded screening programs. Understanding the beliefs and learned health behaviors of these women may help to understand the structure needed to broaden the use of these programs by other women.

This study revealed that some African American women had access to health care within their family of origin as a result of their mother's employment. This informal system of care no longer exists. Understanding if this phenomenon was widespread and how the change from domestic service work to wage earners influences access to health care is worth exploring. Future research needs to explore whether the current plight of African American women and their access to health care has worsened since the 1960's.

A longitudinal examination of the use of screening services would be more indicative of the effects of life course changes. Because the women in this study were in the decade when mammography use is first recommended, we do not know how their use of the services may change with aging and as they face additional life course events and transitions. A longitudinal exploration also would reflect changes in access to breast cancer screening as a result of welfare reform.

Future research should involve intergenerational groups of women to ask mothers and daughters the same questions to better understand the rationale behind certain health messaging. Women within this study reflected their perception of the health messages they received from their mothers. Each believed that they were more open with their current families in the types and content of health messages. A better understanding of the development of learned health behaviors and health messaging would occur through intergenerational research.

Finally, similar questions about learned health behaviors should be asked of men to fully understand the role of women as arbiters of family health. This research reveals the implicit nature of personal responsibility for health among women, but it is not clear if men would receive the same health messaging from their families of origin.

Implications

This research was constructed using qualitative methodology and theoretical frameworks to develop research questions and deliver them in an interview process. The frameworks that served as the foundation for this study were Bengston & Allen (1993) and Price, et al., (2000) life course theory and Bubolz & Sontag (1993) family ecosystem theory. These frameworks affected the design of the research questions. The life course theory (Bengston & Allen, 1993; Price, et al., 2000) asserts that over time the individual within the family as well as the family system change. This informed the use of the family of origin and the current family as a context for understanding health. The family ecosystem (Bubolz & Sontag, 1993) stressed the interaction of the environments surrounding the family and the influence of these environments on the use of services. These two theories functioned to provide a broad context for this research.

The interview process revealed the great influence of the family of origin on learned health behaviors and how women transform this information for use in their current families. These learned health behaviors are adapted with access changing knowledge. The use of ecomaps helped to demonstrate support systems related to the decision-making process. Educators should incorporate this knowledge in programmatic development and construction of resource materials. Practitioners should understand that health behaviors are learned in childhood and develop health delivery approaches that consider the effect of learned health behaviors on current practice. For example, only a few of the women reported learning about prevention (immunization and dental health) within their families of origin yet these behaviors continue in their current families. Researchers should study change in behaviors over the life course to understand the most effective means of facilitating the use of health promotion models of care.

Women are the arbiters of family health and view other women as their support systems for making decisions in conjunction with their health care providers. Learned health behaviors within the family of origin transcended the generations and facilitated the use of breast cancer screening services. Health information from providers and from the media is considered in the decision making process, therefore women need to have knowledge to make appropriate decisions for the use of screening services. Current breast cancer screening programs and media coverage acknowledge the roles that women play in supporting each other in the decision making process. Women need to understand the influence of learned health behaviors and knowledge on decision making related to breast cancer screening. Educators should consider the individualized educational needs of women that facilitate decision-making and understand the sophisticated levels of knowledge accessible to women. Practitioners should determine the support systems available to women in the decision-making processes and family related factors among women who are non-participants in screening. Researchers should study the influence of women as arbiters of family health on decision making related to cancer screening services.

Women have preconceived beliefs about cancer and health behaviors learned within their families of origin. Cancer is feared, yet early detection is recognized as way to diagnosis cancer when it is most treatable. Educators should determine a woman's beliefs about cancer and baseline knowledge before the development of educational programs to incorporate appropriate knowledge. Practitioners need to be aware of women's belief systems and learned health behaviors in understanding non-participation. Researchers should study the influence of health behaviors learned within the family of origin on current health practices.

Parents should realize that they could influence the decision making of future generations by teaching their children appropriate health behaviors. Educators should develop parenting programs that stress the importance of the influence of learned health behaviors. Practitioners in extension programs should include this realization in the development of parenting and health education programs. Researchers should study health behaviors and how families explicitly and implicitly teach about health.

Future Research

While the theories presented formed the foundation for this research and helped to understand learned health behaviors and the use of screening services, the influence of communication within the family is limited. The use of a communication theory may have helped to understand the rationale behind the selective health messaging revealed in this study. Also, while the family ecosystem stresses the decision making processes used within the family in relation to values, needs, goals and standards, it does nothing to understand the barriers faced by women when they decide to use the services and the services are simply, not available. A focus on a communication theory and a social exchange theory would allow investigation in these unexamined areas.

Researcher Reflections

This research began with the intent of understanding decision-making used by women related to breast cancer screening. The decision to interview women that I knew was made after careful consideration of the time I had to complete the work and factors related to trust. I was of the same generation as the women I interviewed and could empathize with many of the ways that these women felt about their relationships with their mothers. Having had relationships with the African American women also reduced any mistrust they may have felt about the intent of this research and reduce any insider/outsider issues. As I reflect on this experience, I find myself focusing on how this experience has changed my practice.

How I have changed

I knew that the result of this study would be the fulfillment of a requirement in completion of my doctorate in family studies. I also knew that I would find something out about the decision making processes women use in deciding whether (or not) to participate in breast cancer screening and family associated factors. I did not anticipate gaining an understanding of the influence of learned health behaviors on decision-making. However, that idea makes sense when I think about the decisions my mother made before her diagnosis of breast cancer. The decisions were the result of learned health behaviors she acquired from her mother and family of origin.

I am much more aware of the role of learned health behaviors on the decision-making processes used by individuals. I reflect on the stories that women have shared with me about their health care decisions, and I realize that experiences of the past influence the present. Consequently, I believe that all health care decision making results from practices learned in childhood, whether related to health promotion, disease prevention, or early detection. I consider this new understanding as I conduct my work at the Cancer Center.

As I work with women from diverse backgrounds I ask questions that will help me to understand the rationale behind their decision-making. I no longer assume that my frame of reference is the same as all other women. As I develop educational materials for use with women from different cultures I am aware of the need to determine if the information "makes sense" from their perspective. It has become clear to me that how individuals respond to the health care system today is dependent upon those behaviors learned in childhood.

Summary

This research contributes to an understanding of the influence of learned health behaviors on the use of breast cancer screening services within a life course and family ecosystem perspective. The data indicated a strong influence from the family of origin on the formation of current health related behaviors. Health care providers need to be aware that consumers of health care have preconceived beliefs and health behaviors learned within their families of origin that influence their decision-making processes. The research would suggest that women have the greatest ability to affect health behavior changes within their families and do so based on the acquisition of knowledge.

The narratives presented illustrate the influence of the family of origin on the development of health beliefs and values. Parents need to be aware that the health messages they relay to their children will change over time with the availability of new knowledge, but that health messages will resonate across the generations for future use. Together families and health care providers can work to disseminate accurate health messages that result in learned health behaviors for the benefit of all.

APPENDICES

Appendix A

Informed Consent (Interview)

FAMILY ECOSYSTEM AND LIFE COURSE FACTORS RELATED TO BREAST CANCER SCREENING

Name: ________________________
Address: ________________________
____

You are being invited to participate in a research project that is studying the relationship of family to breast health and breast cancer screening among women living in Kent County, Michigan and the surrounding community.

If you choose to participate in this project, you will be interviewed by Susan Hoppough, a doctoral candidate at Michigan State University. The interview will take up to three hours of your time. The interview will be audiotaped. To protect your privacy you will select a pseudonym that will be used in place of your name. Only the researcher will know the name assigned to you. In the publication of this study direct quotes will be used. When using direct quotes, the pseudonym will be used in place of your name. Any other responses you offer during the interview will be combined with others, making your response confidential, and your privacy will be protected to the maximum extent allowable by law.

There are no foreseeable risks or discomforts for you associated with participation in this study. There are no immediate benefits for you for participating in this study.

Your participation in this study is voluntary. If you decline participation, you will not be penalized in any way. If you decide to participate, you may choose to withdraw at any time or refuse to answer any questions without penalty. By signing this form, you allow for the use of direct quotes in publications of this study.

If you have questions or concerns related to this project, please contact:

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If you have questions or concerns regarding your rights as a study participant, or are dissatisfied at any time with any aspect of this study, you may contact-anonymously if you wish- Ashir Kumar, M.D., Chair of the University Committee on Research Involving Human Subjects (UCRIHS) by phone: (517) 355-2180, Fax: (517) 432-4503, e-mail: ucrihs@msu.edu, or regular mail: 202 Olds Hall, East Lansing, MI 48824.

Your signature below indicates your willingness to participate. Thank you for your time.

Signature:______________________________ Date:______________

Appendix B

Social Ecomap Instructions

The "ecomap" is a tool to help in understanding you and others with whom you interact. The larger center circle represents you. The smaller circles represent other people, places and groups in your daily life.

To complete the ecomap, please, follow these directions:

1) Fill out the blank spaces of the larger circle with your name, birth date, and names of those in your family/household (e.g., spouse and 2 sons), marital status, total years of education (12 years is high school graduate), and employment status (working full-time, working part-time).

2) See the picture at the bottom right of the ecomap sheet. Using the picture as a guide, draw lines to connect the larger circle with the smaller ones. If there is no relationship between you and a circle, DO NOT draw any line. For example:

- If you have a close relationship with "household members", draw a thick line between the larger circle and the small circle labeled "household members", like this: ▬▬▬▬▬▬

3) For each line, draw arrows to show the direction of the relationship between you and the circle. For example:

- If you have a two-way relationship with your household members, draw 2 arrows (one at each end of the line), like this: ⟷

4) Draw and label circles as needed to tell us about other people, places and groups in your daily life that were not on the drawing.

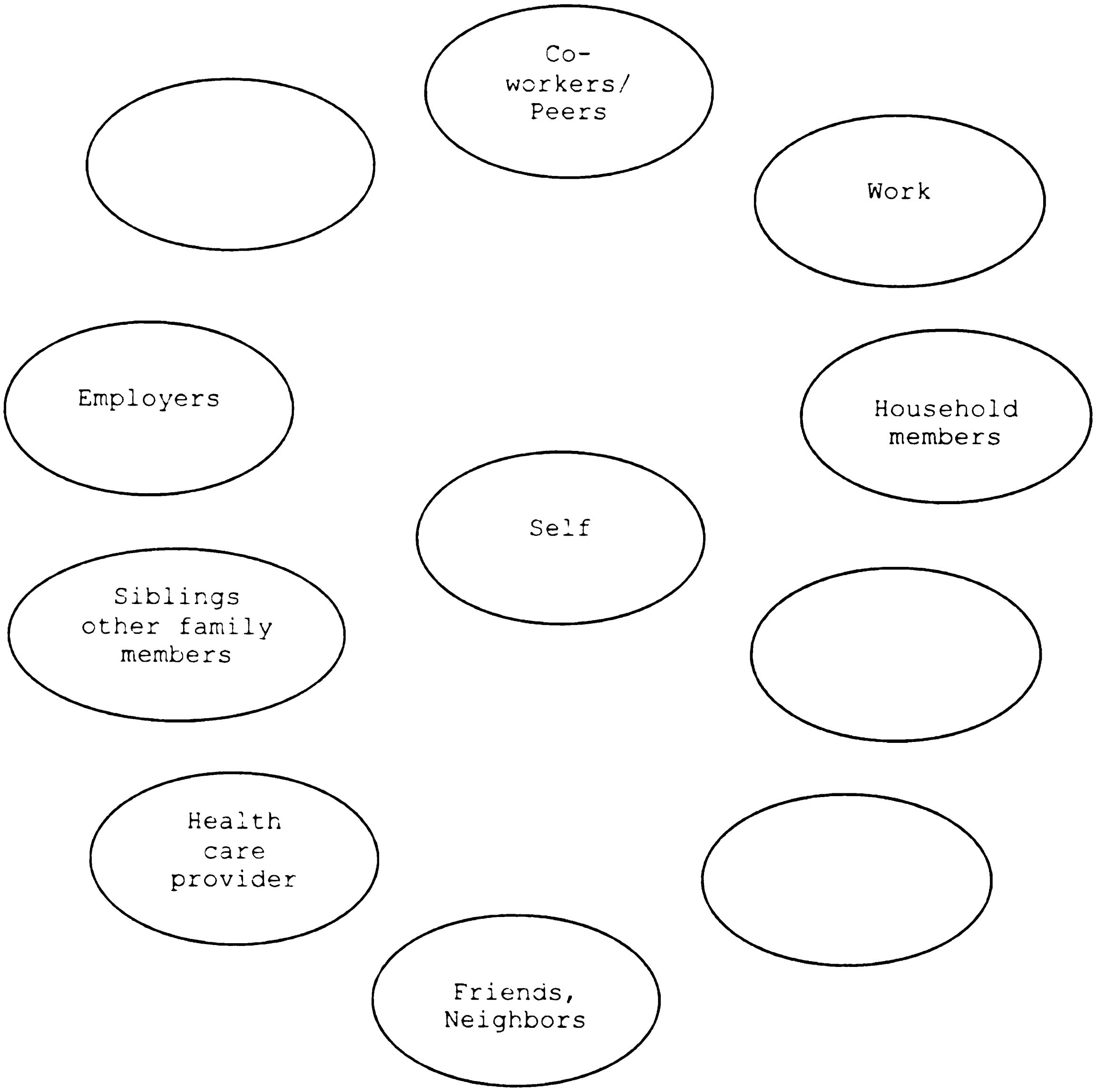
If you have questions about how to complete the ecomap, the interviewer will help you.

Thank you for participating in this study!

Appendix B

Figure 5

Social Ecomap



Name: __________
Birth date: __/__/___
Family/household composition:
____
____
Marital status: ______
Years of education: _____
Employment status: ______

Appendix B

Table 5

Social Ecomap Legend

Relationship Meaning	Line Representation
Conflictual Relationship	〰〰〰
Good Relationship	━━━━━━
Close Relationship	▬▬▬▬▬▬
Distant Relationship	┈┈┈┈┈┈
Stressful Relationship	▬ ▪ ▪ ▬ ▪ ▪
No Relationship	⬭
Directional Energy Flow	━━━━➤

Appendix C

Interview Guide

- Tell me about yourself and why you agreed to participate in this study.
- Suppose you could only use one word to describe yourself. What word would you choose?

Past Experience

- When you were growing up, how did your family define health?
- When you were growing up, how was health discussed in your family?
- Think back to your first memory of an event that was health related. Describe for me the memory? What kinds of decisions do you remember related to this health event? Who was responsible for the decisions that were made?
- What kinds of sayings or adages do you remember your parents or grandparents using to talk about health?
- What kinds of sayings or adages do you remember your parents or grandparents using to talk about cancer?
- As you were growing up, what was the meaning of cancer as defined in your family?

Appendix C

Interview Guide (Continued)

- Think back to the first memory you have about cancer. Describe who was involved and how this memory made you feel.
- What were discussions of cancer like in your family?
- What did your mother or other family member teach you about breast cancer in particular?

Current Experience

- How do you currently define health?
- How is health discussed in your family today?
- Who is responsible for health related decisions in your family and how is this different or similar to the family you were raised in?
- What sayings or adages do you use to talk about health?
- What does cancer mean to you?
- How is cancer discussed in your family today?
- What are you teaching your family about breast cancer in particular?
- Tell me what you know about breast cancer screening?
- Have you scheduled or have you had a mammogram?
- In the decision to (or not to) participate in screening tell me the factors you considered.

Appendix C

Interview Guide (Continued)

Reflection

- What do you think is different about the way health or cancer is discussed in your family today compared with the family you grew up in?
- What is different about those viewed as responsible for family health today compared with the family in which you grew up?
- Is cancer and cancer screening discussed/viewed differently in your family today than the family in which you grew up? If so, how different? If not, how the same?

How many years have you been married? How many children do you have? What are their ages? Are your parents living? If so, do they live close to you or far away? How many brothers or sisters?

Appendix D

Table 6

Culture Specific Attributes*

CULTURE SPECIFIC ATTRIBUTE	COLLECTIVISM EXPRESSION	INDIVIDUALISM EXPRESSION
Self-perception	Groups are basic units of social perception. Sets of relationships organized around an individual.	Individuals=basic units of social perception. Focus on the individual.
Attributions	Attribute events to external causes.	Attribute events to internal causes.
Identity and emotion	Identity defined by relationships and group membership. Emotions are other focused and short.	Identity based on what they own and their experiences. Emotions are ego-focused and long duration.
Cognitions	Think about needs of the in group.	Focus on personal needs and rights.
Motivation	Reflection of receptivity and adjustment to others needs.	Reflection= internal needs, rights…can withstand social pressure.
Attitudes	Reflection of sociability, interdependence, family integrity.	Reflection of self-reliance, hedonism, competition and emotional detachment.
Norms	Consensus concerning the roles of men and women. Use equality or need to distribute resources.	Lack of consensus about the roles of men and women.
Values	Family security, social order, respect for traditions, honor parents/elders, security, politeness.	Curiosity, broadmindedness, creativity, exciting and varied life, pleasures.
Social behavior	Shift behavior contextually (with in group versus out group) resulting in less evident personality.	Non-shift of behavior, personality evident regardless of group relationship.
Attitudes toward privacy	Personal business is group business.	People should mind their own business, respect of privacy.
Communication	Emphasis on context concern for the feelings of others.	Emphasis on clarity.
Responsibility	Collective responsible for wrongdoing of one of its members.	Individual responsible for wrongdoing.
Professional Behavior	Select, evaluate and promote based on loyalty and seniority rather than personal attributes.	Use personal attributes than group membership.

*Adapted from Triandis, H. C. (1995). *Individualism and collectivism.* Oxford: Westview Press.

Appendix E

Table 6

Ecomap: Social Relationships

Name	A*	B*	C*	D*	E*	F*	G*
Kim	→		↔	┈┈			⬌
Coffy	↔	⬌		┈▶	◀┈▶		
Maya	⬌		↔	↔		⬌	
Sojo	←〰		◀┈▶	←		⬌	
Rose	〰	↔		↔	⬭		↔
Amy	↔		↔	↔			
Hayley	→	⬌		—	⬭		
Bambi	⬭	⬌		┈▶	┈┈	⬌	
Cissie	—	↔		←	⬭		
Yvonne	⬌	⬌		↔	↔	⬌	

*A=Church, B=Friend, C=Friend/Neighbor, D=Health Care Provider, E=Neighbor, F=Social Group, G=Education

Appendix E (Continued)

Table 7

Ecomap: Family Relationships

Name	*H	*I	*J	*K	*L	*M	*N
Kim				➡	〰		
Coffy		⬌			↔		
Maya				⬌	⬌		
Sojo	↜			┈	⬌		
Rose		⬌	⬌	⬌	◀┈▶		
Amy	⬌	↜		⬌			– ▶
Hayley			↔		⬌		
Bambi				⬌	↜		
Cissie		– ▶	⬌		⬌	⬌	
Yvonne				⬌	⬌		

* H=Father, I=Mother, J=Daughter/Son, K=Household Member, L=Siblings, M=Significant Other, N=Sister

Appendix E (Continued)

Table 8

Ecomap: Work Relationships

Name	Coworker	Employer	Manager	Work
Kim	⬌	←		→
Coffy	↔	↔		↔
Maya	⬌	→		⬌
Sojo	↭	↔	⬌	↭
Rose	↔	↔		↔
Amy	↔	↔		↔
Hayley	↔	⬌		↔
Bambi	⬅ ·	↔		→
Cissie	⬌	↔		⬌
Yvonne	◀┈┈▶	↔		⬌

Appendix E (Continued)

Table 9

Ecomap: Results Legend

Relationship	Legend Symbol
Conflictual	∿∿∿
Good	—
Close	━
Distant	••••••••
Stressful	▬ ▪ ▬
None	⬭
Flow of Energy	
Away From	➡
Toward	⬅
Bi-directional	⬌

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