

Ring of Silence: African American Women's Experiences Related to their Breasts and Breast Cancer Screening

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The purpose of this study was to explore women's memories and feelings concerning their breasts and breast cancer screening experiences in relation to their current breast cancer screening behaviors. Twelve African American women shared stories that were generated in written narratives and individual interviews. Two core themes emerged from the data analysis: silence and societal contradictions. On further review and interpretation of the core themes, one integrative theme became apparent: Ring of silence. Contradictory messages women receive from society, both voiced and unvoiced, can have a long-term effect on how some women perceive their bodies, and how they value early detection related to breast cancer screening. Key Words: Narratives, Breast Cancer Screening, and African American Women

Introduction

Western values and traditions have oppressed women with the message that without breasts, women are not whole (Mackel, 2000). The female breasts are often seen as symbols of sexuality, femininity, and motherhood. It is frequently difficult for women to sort out their own feelings about their breasts from the messages that women receive from embedded cultural values, social interactions, individual experiences, and the media. For the most part, women have allowed their breasts to be defined by others' viewpoints, and have allowed their own views to get lost in the shuffle. Western society appears to be breast obsessed, and many American women fear losing their breasts from breast cancer more than dying from it (Ferguson & Kasper, 2000).

Many women still experience a sense that discussion of breast cancer should be repressed. There has been a persistent idea that cancer of any sort should not be controlled, possibly because cancer itself is perceived by some as uncontrollable. Another reason women may be hesitant to openly discuss breast cancer is that open dialogue about women's breasts is usually not considered appropriate in general conversation. Discussions and comments about breasts, other than in a sexual context, are typically subdued. This seems to be paradoxical. Breasts are typically viewed as inappropriate for discussion because they are often perceived as sexual organs: However, the only socially acceptable way to talk about breasts in this society has been to talk about them as sexual objects.

In an exploratory study of 12 middle to high income African American women, all college graduates aged 42 to 64 years; stories about experiences related to the participants' breasts were collected. The primary aim of this study was to ascertain whether there is an association between women's experiences related to their breasts and

their current breast cancer screening behaviors. Therefore, the primary research question was, “Is there an association between women’s experiences related to their breasts and their current breast cancer screening behaviors?” This study was guided by critical social theory (CST) within a feminist perspective. Previous studies addressing the breast cancer screening behaviors of African American women have not examined the possible association between current breast cancer screening behaviors and women’s memories and feelings concerning their breasts and breast cancer screening experiences. While retaining the goals of CST, emancipation and enlightenment, a feminist perspective not only allowed me to describe and interpret phenomena of women’s lives, but it also raised consciousness about breast cancer and breast cancer screening, and may bring about changes in the screening behaviors of the women who participated in this study (Hall & Stevens, 1991).

Evolution of the Study

As a female African American health care professional, the author has an impassioned interest in health promotion issues, particularly minority women’s health concerns. Very early in my academic endeavors, I completed a review of empirical studies that focused on African American women’s cancer beliefs and cancer screening behaviors. It quickly became apparent to me that the majority of research regarding minority health issues typically identified socioeconomic status as the overriding cause of disparities in minority health outcomes. The literature consistently emphasized the fact that low income and access to care are the primary barriers identified as the cause of health disparities in ethnic/minority populations. I did not dispute this claim, but began to reflect on my own health promotion behaviors, in particular, my breast cancer screening behaviors. As an African American and a college graduate with access to care, I admit to not follow the recommended guidelines for breast cancer screening. I began to casually question my peers and other African American women who were college graduates, with access to health care, about their breast cancer screening practices. The results of these informal interviews and findings from this study coincide with findings from similar studies documented in the literature.

Hailey and Bradford (1991) reported that a majority of African American college women aged 20 years and older did not practice breast self-examination (BSE). Phillips and Wilbur (1995) conducted a study that included a sample of 154 African American women of differing employment status to address the socioeconomic variables of income and education. Their sample included women who were unemployed, service workers, and teachers. For the purpose of their study, teachers were selected to reflect a group of employed and middle-income African American women, service workers were selected to reflect a group of employed and low-income African American women, and unemployed women were selected to reflect a group of women living in poverty. These researchers found that women with some college or a college degree were least likely to practice monthly BSE compared with non-college graduates. Among women with private health insurance, only 27% of African American women received mammograms (Baker, 1992; Blustein, 1995). It became evident to the author that there are reasons other than socioeconomics, cultural barriers, and access to care, the factors currently identified in

the literature that dissuade African American women from participating in breast cancer screening activities.

The purpose of this study was to gain insight and a better understanding of barriers to breast cancer screening that have not been previously identified in the literature, by exploring African American women's experiences across the life span in relation to their current breast cancer screening behaviors. Clandinin and Connelly (1994) acknowledge that experience cannot speak for itself and that all we have is a representation of experience in the form of text. Therefore, the author asked women to share written stories and audiotaped interviews about times in their lives when their breasts may have been particularly important to them and about their breast cancer screening experiences.

Background

Behavior change and health behavior models often minimize individual differences and exclude variability of recognized risks based on race, sex, social class, and culture (Price, Desmond, Slenker, Smith, & Stewart, 1992; Turner & Kiecolt, 1984). These models do not take into account the possibility of potentially emotional components of health-seeking behaviors such as experiences or memories and feelings about a particular phenomenon; for example, past mammography screening experiences or other experiences regarding women's breasts. Experiences across the life span and perceptions about those experiences could be a factor in explaining present health behaviors related to breast cancer screening. I agree with Ferguson and Kasper (2000) when they explain that the breast cancer screening behaviors of minority women relate not only to the larger picture of social, economic, and cultural oppression, but also to gender issues of being a woman or an ethnic minority woman in the United States.

Although the literature on ethnic minority women's breast cancer screening behaviors is substantial, researchers have not explored women's experiences across the life span, in relation to their breasts and their current breast cancer screening behaviors. Two studies have been documented in the literature that explored women's past experiences related to breast cancer or breast cancer screening. Hatch et al. (1999) conducted a study with 11 Hispanic and 6 White women to elicit their memories of early life events for the purpose of developing and pilot testing a culture-specific questionnaire, to retrospectively assess peripubertal breast cancer risk factors. Participants were volunteer breast cancer survivors or relatives of survivors. These researchers found that "to enhance the validity of retrospective data on peripubertal breast cancer risk factors, it is important to take account of cultural differences" (p. 269). Phillips, Cohen, and Tarzian (2001) used a hermeneutic phenomenological approach to interview 23 low and middle income African American women to gain an understanding of women's experiences with breast cancer screening. This study described the experience and meaning of breast cancer screening for African American women and showed that the women in their study desired a "holistic approach to health that did not separate the breast from the rest of the body" (p. 139) and that "interventions for African American women should include a focus on minding the body, self, and spirit to promote breast cancer screening" (p. 143). In one other study, not related to breast cancer screening behaviors, Redelmeier, Rozin, and Kahneman (1993) found that patients sometimes make decisions based on intuitive

feelings that have been affected by emotions related to memories about events that occurred in the past.

The current study addresses gaps in the literature by adding new insights regarding women's experiences across the life span in relation to their current health behaviors related to breast cancer screening. Although this area of research is in a stage of development, findings from my preliminary work (Thomas, 2004) strongly suggest there is a clear association between women's experiences across the life span pertaining to their breasts and their current breast cancer screening behaviors. To date, other than preliminary data obtained by this author, researchers have not explored women's experiences across the life span in relation to their current health behaviors. Findings from my preliminary work serve as a starting point that will support a theory-building opportunity directed toward the development of culturally acceptable health behavior or explanatory models that have an ecological focus rather than individual focus. Ecological models are health-promotion models that are concerned with environmental change (e.g., homes and communities), behavior, and policies that help individuals make healthy choices (Stokols, Pelletier, & Fielding, 1996). As a result, future breast cancer screening interventions can be more effective and acceptable to the ethnic minority populations studied.

Significance of the Problem

The American Cancer Society (ACS) estimated that in 2004, approximately 215,990 women in the United States were diagnosed with invasive breast cancer (Stages I-IV), and another 59,390 women were diagnosed with in situ (has not spread to surrounding fatty tissues in the breast or to other organs in the body) breast cancer (ACS, 2003). Since 1986, female breast cancer rates have increased by 0.6% each year, and in situ breast cancer incidence rates have increased by 6.1% over the same period (Weir et al., 2003). Deaths attributed to breast cancer will occur disproportionately among women from ethnic minority groups. Despite access to free health care, researchers found that ethnic minority women presented with more Stage II tumors at diagnosis than White women (Zaloznik, 1997). The stage of a breast cancer describes the size of the tumor and extent of lymph node involvement. A Stage I breast cancer tumor is less than 2 centimeters with no lymph node involvement. A Stage II breast cancer tumor is from 2 to 5 centimeters with either no lymph node involvement or lymph node involvement on the same side as the breast. African American women experience a higher mortality rate and lower survival rate than White women of comparable age and cancer stage. The 5-year survival rate for breast cancer in African American women is 63% compared with 78% for White non-Hispanic women (ACS). Nearly half (47%) of all African American women diagnosed with invasive breast cancer will die from the disease within 10 years (Pisani, Parkin, Bray, & Ferlay, 1999).

According to the ACS, the key to surviving breast cancer is early detection and treatment. In addition to annual mammography, annual clinical breast examinations (CBE) are recommended for women aged 40 years and older, and CBE is recommended every 1 to 3 years for women younger than age 40 as a means of secondary prevention and early detection of breast cancer. Despite campaigns for early breast cancer detection for all women, women often do not follow the recommended screening guidelines. A new

approach to exploring barriers to breast cancer screening is needed if health care professionals are to have an impact on this trend. The ACS has stated the objective of increasing mammography screening to 90% by the year 2015 (ACS, 2003). An important roadblock to this goal is the predicted population growth. The U.S. Census Bureau (2002) predicts that the size of the African American population will double by the year 2020. Therefore, it is essential that health care researchers and providers explore other avenues to better understand barriers specific to mammography screening if early diagnosis and treatment of breast cancer are to be increased among ethnic minority women.

Theoretical Perspectives

Feminist scholarship and CST take into consideration the social context represented in the lived experience of the participants. The focus of CST is not to do research on people, but to conduct research with and for people, while eliminating the subtle implication that the researcher is the person of authority and power (Meyer, 1993). CST focuses on the lived experiences of people and implies direct researcher-participant interaction. As defined by Streubert and Carpenter (1999), CST is “a philosophy of science based on a belief that revealing unrecognized forces [conceivably past experiences] that control human behavior will liberate and empower individuals” (p. 330).

While retaining the goals of CST, emancipation and enlightenment, a feminist perspective supported this study’s development of a focused approach to review the narratives of African American women’s stories as distinctly woman-centered and gave voice to African American women’s unique experiences. “Feminist scholarship endeavors not only to describe and interpret phenomena of women’s lives but also to raise consciousness and bring about changes in the interest of the women studied” (Hall & Stevens, 1991, p. 16). Women’s interpretations, values, and actions can differ dramatically according to class, race, ethnicity, education, age, sexual orientation, and national origin (Joseph & Lewis, 1981). I acknowledge that each woman’s experience is unique, and I reflexively interpreted the influence of the context (past experiences) on the phenomenon (current breast cancer screening behaviors). In other words, I made a conscious effort to remain aware of my personal perceptions and assumptions, and was conscious of how personal preconceptions may affect the research process.

The use of feminist scholarship in this study helped me see the patterns and interrelationships as well as implications for questions that an inquiry from a nonfeminist perspective may not have made visible (Reinharz, 1992). The United States, a culture immersed in Western values and traditions, may be better understood by examining these issues through a feminist perspective within the framework of CST. Both perspectives were congruent with the purpose of this inquiry because feminist scholarship and CST share dimensions of fostering self-consciousness (Ray, 1992).

Methods

This qualitative, exploratory study used narrative methods to generate data. The purpose of narrative methods in research is to gain an understanding of how people think or act in the contexts in which they live through their stories. The context was

experiences related to women's breasts; how they act related to the participants' current breast cancer screening behaviors. Narrative inquiry, based on the views of Clandinin and Connelly (1994), is focused on understanding experience as being situational, continual, and interactive; the study of the ways humans experience the world. I asked the women to share written narratives about specific events that occurred throughout their lives related to their breasts, their mammography screening experiences, and their current breast cancer screening behaviors. Inquiry into a story, or narrative inquiry, is considered by some the method of choice for the study of human action (Polkinghorne, 1988). This was an exploration of the ways women have experienced the world in relation to their breasts. For the purpose of this study, no distinction was made between the terms *stories* and *narratives* because there are many definitions in the literature: The terms were used interchangeably. The focus of this study was on conducting research with first-person accounts of experiences related to women's breasts and breast cancer screening experiences and behaviors. The primary aim of this study is to ascertain whether there is an association between women's past experiences related to their breasts and their current breast cancer screening behaviors.

Participants and Recruitment

Twelve professional African American women participated in the study. Criteria for participation included being an African American woman without a history of breast cancer, between 40 and 64 years of age, with at least an associate's degree in any discipline and health insurance. The decision to select this age range was based on the ACS breast cancer screening guidelines. Although the ACS recommends beginning BSE at 20 years of age, at age 40 all three screening modalities are recommended, and women at this age are more likely to have graduated from a college degree program.

Recruitment flyers were initially sent to female pastors or the wives of pastors from local African American churches: This strategy was not at all helpful in obtaining the sample. None of the participants were recruited from the churches: However, a diverse sample of middle-income women (age, education, and occupation) was obtained by mailing and personally delivering recruitment flyers to local hospitals, secondary and post-secondary schools, and through word-of-mouth referrals from the initial study participants.

The median age of the participants was 56 years, ranging from 42 to 63 years. One participant had an associate's degree, 7 had bachelor's degrees, 2 had master's degrees, and 2 had doctorate degrees. The study was reviewed and approved by a university institutional review board. Consent was obtained from each participant before the start of data collection. All participants were asked to choose a pseudonym for identification purposes. The women were asked to share stories about their experiences regarding breasts and cancer, specifically stories about their breasts and breast cancer screening experiences.

Data Generation

A total of 12 narratives and 12 follow-up individual, face-to-face interviews provided the data for this study. Redundancy of responses occurred, and continued data

collection at the end of the study added little new information. Collection of the narratives and completion of the follow-up interviews took place in an urban area of a large midwestern city. The intention of this inquiry was to capture personal depth regarding each woman's experiences: Therefore, the author chose to use individual narratives and interviews as the method of data collection. Both the narratives and audiotaped interviews allowed the author time to capture the participants' stories in their own words. This method of data collection allowed the women time to reflect on times in their lives when their breasts were significant to them. Included in the participant instructions was a list of topics to help women remember significant events concerning their breasts. Participants were asked to share stories about puberty and breast development, breast-feeding experiences, changes in their breasts as a result of the aging process, and any other topic related to their breasts that they felt comfortable sharing.

Prospective participants contacted the author by telephone to express an interest in taking part in the study. The author met in person with each participant individually at their homes to explain the purpose of the study, to obtain written informed consent, and to give the women a blank notebook in which to write their narratives. The women were instructed to write stories about experiences related to their breasts and at least one story about a mammography screening experience. A follow-up telephone call was made to each study participant within 1 week after obtaining informed consent. The purpose of this telephone contact was to clarify questions that may have transpired from the time of signing the consent, to encourage participants to write their stories, and to schedule a time to pick up the completed narratives.

I returned 3 to 4 weeks later to pick up the completed narratives. A complete narrative consisted of at least two stories about an experience related to the participants' breasts and one story about a breast cancer screening experience. Approximately 2 weeks after the narratives were returned, they were transcribed verbatim by a paid transcriptionist, and reviewed and checked for accuracy. I met with each woman individually to conduct a follow-up face-to-face audiotaped interview. This 2-week period allowed the author time to reflect on the journal entries and compose questions specific to each individual participant. The purpose of the follow-up interview was to allow the women to elaborate on their stories, to provide clarification if necessary, and to discuss their current breast cancer screening behaviors. The use of narratives and follow-up interviews with a researcher of the same racial and socioeconomic background fostered a safe environment for the women to reflect on their own life experiences and share stories that they may have kept silent in the past. Data collection of the narratives and completion of the follow-up interviews took place over a 5-month period.

Questions for the face-to-face interviews were developed from the stories for each individual participant. One example of an interview question was

You along with several other participants used the word *womanhood* several times in your narratives when discussing your experiences during puberty and breast development. Will you define for me what you mean by the term; what is your definition of the term womanhood?

During the follow-up interviews, each woman was asked to describe her current breast cancer screening behaviors. The process of eliciting written narratives in conjunction

with follow-up interviews provided for saturation of data and increased the rigor of the study. In addition, multiple contacts with the participants, in person and by telephone, and multiple methods of data collection (narratives and interviews) contributed to the trustworthiness of the data. The author made a conscious effort to follow, rather than lead, the direction of the interviews by asking the participants for clarification of definitions, slang words, and metaphors. Both CST and feminist scholarship require that an objective stance and a voice of authority be avoided.

Data Analysis

Analysis involved constructing, in text form, each woman's story. In other words, the written narratives and the transcribed interviews were combined to allow for a continuous flow in each participant's stories. Particular attention was paid to retaining the individual voice of each participant by writing the narrative excerpts in the participants' own words. Occasionally, but infrequently, small sections were omitted that were considered irrelevant (did not pertain to stories related to their breasts) and, at times, the sentence structure of the text was changed to facilitate readability.

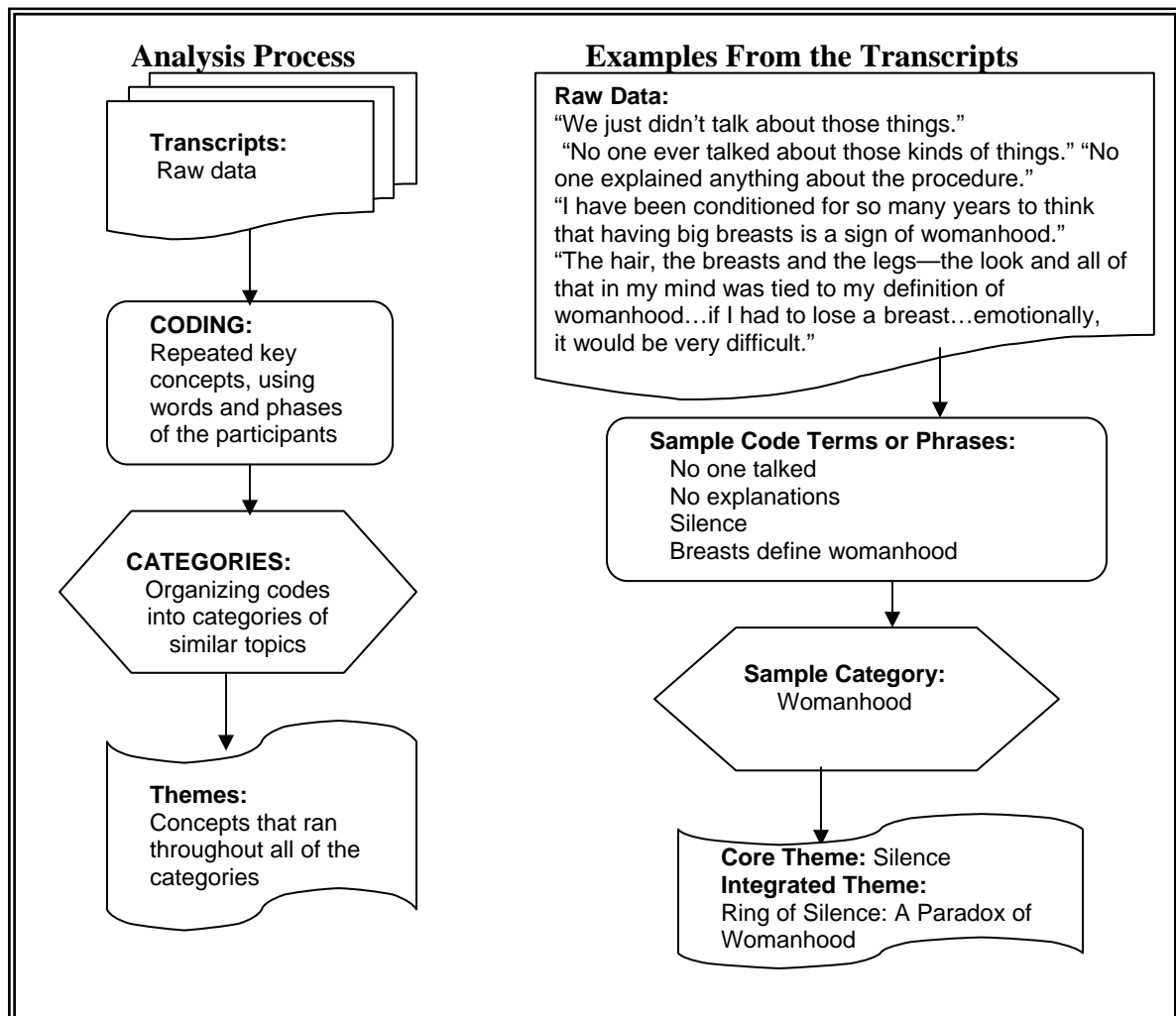
Each transcript (combined written narrative and interview transcript) was typed into a Word document, then entered into ATLAS.ti, and coded inductively line by line to identify recurrent patterns, similarities, and differences in the individual and collective narratives (Muhr, 2000). ATLAS.ti is a software tool used for the management, evaluation, and visualization of qualitative data. This software program provides support by facilitating text analysis, particularly in coding, annotating, and comparing segments of the data. In addition, ATLAS.ti allows an overview of the entire project and has a search and retrieval function, making it easier for the researcher to synthesize all of the data segments and notes relevant to a specific idea or theme. This software program allowed the author to work on sections of the data without losing perspective of the whole and aided in revealing unanticipated epiphanies.

Line-by-line coding of the transcripts was the first stage in the analysis process. Initial descriptive coding, using the words or phrases of the participants, involved looking for repetition within and across the transcripts. After the coding process was completed for each transcript, the list of codes was examined to identify common concepts that illustrated the participants' experiences, descriptions, and definitions. Similar code terms and phrases were grouped together and then regrouped to include all of the identified concepts into categories of similar topics. Redundant codes were discarded. Looking for relationships, the categories were re-sorted into groups of similar content and meaning. The author identified dominant categories by recognizing code words or phrases that were consistently repeated within and across the transcripts. Inductive codes are codes or concepts that are developed by the researcher through direct examination of the transcripts. For example, phrases that referred to participants' relationships with their mothers or other women in their lives were coded as "female influences." In some instances, more than one code (co-occurring codes) was attached to the same line of text. Frequently occurring concepts (codes) were examined for their significance and interrelationships among all aspects of the data.

The second phase of analysis involved organizing the codes into clusters of similar topics and reorganizing the clusters of codes into related categories. Categories

are defined as a group of codes having common elements that relate to particular sets of patterns or recurrences. Categories of related codes were then grouped to reflect themes. Themes represent the interpretive link between the original transcripts and the researcher’s theoretical concepts (Seidel & Kelle, 1995). The author was attentive to the recognition of repetition within and across the transcripts, metaphors, historical explanations, and descriptions. This aided in the identification of themes found in the content and context of the individual and collective transcripts. This form of analysis assisted the author in revealing themes that ran throughout the language and culture of individual participants. Rather than separating women’s experiences from the contexts in which they occur, feminist scholarship recognizes women’s experiences as inextricably connected to the larger political, social, and economic environment (Hall & Stevens, 1991). Figure 1 provides a description of the analysis process.

Figure 1. Description of the data analysis process.



The final phase of analysis involved a second review of the transcripts and review of the categories in an attempt to describe themes that embraced the collection of stories (Polkinghorne, 1995). For the purpose of this inquiry, themes were identified as

categories that connected elements of the stories or links identified in the individual and collective transcripts. Themes were attributed to the group, rather than to individuals, as the unit of analysis.

Participant comments and researcher insights were revealed using a four-column analysis grid for qualitative inquiry (F. Reeder, personal communication, December 15, 2001). Table 1 provides an example of a method the author used to identify researcher insight and theoretical or other perspectives from the raw data.

Table 1

Four-Column Analysis Grid for Qualitative Inquiry

Participant's Experience	Participant's Comments	Researcher's Insights	Theoretical or Other Perspectives
Junior high school	"I noticed that I was the only girl not wearing a bra."	Girls very early compare their bodies and form self-images by comparing themselves with their peers.	"The physical self appears to be the most important predictor of self-image among African American youth" (Jackson & Mustillo, 2001, p. 35).
Aging breasts	"I never really paid much attention to my breasts until my mid-thirties, that was definitely an "oh-my!" moment."	The women were surprised by the physical changes that occur to breasts because of the aging process.	There has been little focus on educating women about the physical changes that occur to the breasts because of the aging process.
Breast development and early experiences	"They never spoke about them." "I didn't want them, didn't need them."	I noticed the women often referred to their breasts as <i>it</i> or <i>them</i> instead of <i>my breasts</i> .	Women may not realize that they often do not take ownership of their breasts.

Qualitative Rigor

Two methods used to establish rigor in qualitative studies are peer debriefing and member checks. Peer debriefing was obtained by asking peers experienced in qualitative data analysis to review several transcripts and discuss the coding process to check for emergent themes and ideas (Holloway, 1997). Member checking involved returning to those from whom data was collected and testing out emergent themes to ensure that the

themes were recognized by the participants as accurate representations of their views and experiences: Therefore, each of the 12 participants received a copy of her complete transcript and the authors' interpretation of the data. Eight women reviewed and edited their individual transcripts. For unknown reasons, the remaining 4 participants chose not to review their transcripts. None of the 8 women made any significant changes or additions to their transcripts.

Because the author met the criteria for participating in this study, she was particularly vigilant about asking for clarification and not making assumptions about the women's descriptions, explanations, and discussions of their stories and responses to the interview questions. Overall, review of the transcripts with the participants individually and review of the coding process with experienced qualitative researchers contributed not only to the rigor of the study, but aided in providing insight regarding the exploration of women's experiences across the life span in relation to their current breast cancer screening behaviors.

In addition, credibility was achieved by checking for the representativeness of the data as a whole. This was done by reviewing the individual transcripts and looking for similarities within and across the participant transcripts. "A qualitative study is considered credible when it presents such accurate descriptions or interpretations of human experience that people who also share that experience would immediately recognize the descriptions" (Krefting, 1991, p. 218). A final version of the findings was sent to all participants. Participant perspectives of the research findings may increase the relevance and acceptance of findings among the persons for which the study is intended to address (Ong, 1996). The transcripts and the findings, written using the words of the participants, added to the credibility of this study. Finally, trustworthiness was established in a number of ways. Multiple contacts with the participants, in person and by telephone, and multiple methods of data collection (journals and interviews) contributed to the trustworthiness of the data. In addition, the involvement of peers during the coding process aided in reducing bias that can occur when a single researcher analyzes text.

Findings

As a result of reviewing and questioning relationships between the categories, and looking for conceptual coherence in the data, two core themes emerged from the data analysis: *silence* and *societal contradictions*. These core themes were woven throughout the entire collection of narratives. See Thomas (2004) for an in-depth discussion of the categories.

Core Theme: Silence

The core theme of *silence* was used to reflect the consistent recurrence of stories about the experience of not knowing and being scared because "nobody talked." Silence and secrecy were threads woven throughout all of the women's stories about their breasts and breast cancer screening experiences. For example, in the category, *Seasons of Breast Awareness*, participants shared, "She [her mother, who was a nurse] didn't talk about personal things like sexuality and puberty" and "No one ever talked about those things." Another participant explained, "No one ever talked about those kinds of things. I was so

naïve about my body and the different changes that were taking place.” One woman stated, “I had no idea why my mother and aunts would look at me, snicker, and under their breath, make hushed comments about ‘bumps’ and ‘mosquito bites’ and ‘nipples.’” Another participant explained,

My parents never talked to me about sex, sexuality, or body changes. As a result, I recall the changes that took place in my pubescent body were veiled in confusion that I, alone, had to make sense of for myself.

One woman described her experience of unintentionally discovering a family secret that was very frightening for her.

My grandmother had large breasts but I never knew that she only had one breast until early one morning when I was about 7 years old. I went into the bathroom while my grandmother was washing up at the sink. I just happened to look up at my grandmother and ran out of the bathroom screaming. I started screaming because I was so afraid of her breasts. It looked like someone had tore off her breast and it had started to grow back. It was all jagged and raw looking. It was so scary. I woke everyone up with my crying and screaming. I could not talk and all the adults were whispering to each other. I really became afraid to go to my grandmother’s house after that experience. No one in my family ever talked about my grandmother’s cancer or her breast surgery. No one explained to me what had happened to her until I was in my 20s. It seems that it was a secret that we were not supposed to tell or talk about even amongst ourselves. So, it became a source of fear for me. No one ever volunteered any information about my grandmother. I finally learned about breast cancer and breast surgery from other students when I was at college.

Silence in the English language is often described as the opposite of speech, language, or expression. In the United States, silence is considered passive; in China and Japan, it traditionally signals pensiveness, alertness, and sensitivity (Wheeler, O’Friel, & Cheung, 1994). The Chinese and Japanese character for silence, on the other hand, is synonymous with noise, motion, and commotion. According to Greene (2002, p. 45),

Silence works in multiple ways in everyday talk and can represent one’s social values and beliefs. Linguists refer to silence as a speech act or part of speech, but cultural theorists see silence and mutedness as representations of public expressions of self.

In *Voice and Silence in E. E. Cummings’ Poetry*, Alfandary (2000, p. 37) describes silence in the following way,

Silence is a perquisite for the voice, a space for it to invest, a resonance chamber in which to reverberate. In silence resounds voice, in voice

silence is present. Silence is more than just an idea or a thing; it is a phenomenon, a form for emotion to occur.

In the category *Breast Cancer and Cancer Beliefs*, another woman shared, “My mother, whenever she talks about cancer...she whispers.” Examples of *silence* as a theme also became apparent in the stories that centered around discussions of breast cancer screening experiences, when, for example, participants shared, “No one explained anything about the procedure,” “I went in cold turkey,” and “No one really explained the procedure; I didn’t know what to expect.”

The women wrote about and discussed their feelings of shame, confusion, and inadequacy because of the silence and secrecy they experienced or perceived during their early years of breast development. As one participant explained, “The fact that they whispered about these mystical protrusions among themselves but did not talk to me made these ‘pop-ups’ an even greater source of stigma and shame.”

In *Listening to Silences*, Hedges and Fishken (1994) wrote about “the centrality of silence in women’s culture, specifically the ways in which women’s voices have gone unheard.” Women’s attempts to be heard have often been considered as “outbursts” and “neurotic” (Hedges & Fishke). Much of women’s writing about silence is about the ways in which men and society have silenced them and the resultant feelings of shame, guilt, and sometimes anger (often silent) that is set free when they recognize this. For 9 of the participants in this study, mothers often unknowingly silenced their daughters and instilled feelings of shame and guilt.

Another illustration of the core theme *silence* was reflected in the closing summary of one participant’s narrative.

I think the only way we can change that [the fact that “nobody talked” and “the secrets”] is with more information and talking about it [cancer, breast development, and breast cancer] because when we try to keep it a secret, the secret gets more secret.

Core Theme: Societal Contradictions

The majority of research studies regarding body image focus on behavioral aspects related to eating disorders. However, negative body image can conceivably have an impact on health promotion behaviors, such as breast cancer screening. The ideal female body portrayed in magazines appealing to men continues to be large-breasted women (Koff, 1998). In addition, society’s construction of feminine beauty represented in women’s beauty and fashion magazines reinforces stereotyped portrayals of femininity (Andsager, Hust, & Powers, 2000).

The second core theme, *societal contradictions*, was used to describe the spoken, tacit, and underlying mixed messages that are sent to women from a variety of sources such as the media, parents, peers, male partners, the health care system, and Western society in general. One participant stated

I think medicine treats women different from the way they treat men. Women are gullible about anything, weight loss, fashion, they tell us

anything and we just jump to anything they say...and it's like anything we do as females; we have to do it once a year. You have to do it; we're forced to do these yearly examinations.

Negative body image can have profound effects on women's self-perceptions, psychological functioning, and behavior. One participant shared, "This society is so focused on youth and that [youth] being equated with beauty and all the rest of that. The sagging breasts are just kind of like the last straw; everything is going south." In addition, another participant shared, "Society tells us that the bigger the breast, the sexier you are. Nowadays they have good technology to make [women's] breasts better than the ones you have, the ones you were born with."

Studies involving women with and without breast cancer and studies involving postmastectomy patients documented findings linking breast dissatisfaction with psychological distress such as self-consciousness, diminished self-esteem, and doubts about one's femininity (Grant, 1996; Koff, 1998). According to Wilmoth (2001), "A woman's definition of self is based on a lifetime of feedback about having breasts, menstruating, and being able to engage comfortably in sexual activity. Breast cancer threatens this self-perception" (p. 283). For the most part, the participants agreed that the messages from society play a significant role in women's self-identity. For example, a participant explained, "Society wants you to believe that it [womanhood] is defined by certain bodily measurements, but no, it [womanhood] is learned behavior and it [womanhood] is a conditioned response to how you view yourself."

"There is one major body area—breasts, for which the relationship between size and satisfaction, as well as the implications for body image and psychosocial functioning, appear to be more complex" (Mazur, 1986, p. 282). Historically, men, the media, and the movies have defined women's images. The media also portray the idea that a woman's success and happiness depend on certain physical attributes. In other cultures, such as in Africa, the level of a girl's maturity, wisdom, and self-discipline determines womanhood. For the most part, in Western society, men decide if a female is a woman based on how she looks—if she has breasts and curves. Loss of virginity and pregnancy are also definitions of womanhood in our culture. One participant shared, "Society wants you to believe that womanhood is defined by certain bodily measurements...I have been conditioned for so many years to think that having big breasts is a sign of womanhood." The image or ideals of feminine beauty have been formed by fashion, art, and the media, particularly women's magazines or magazines focused on the female reader. These ideals could be perceived as oppressive social expectations that distort women's self-identity, body image, and personal definitions of womanhood.

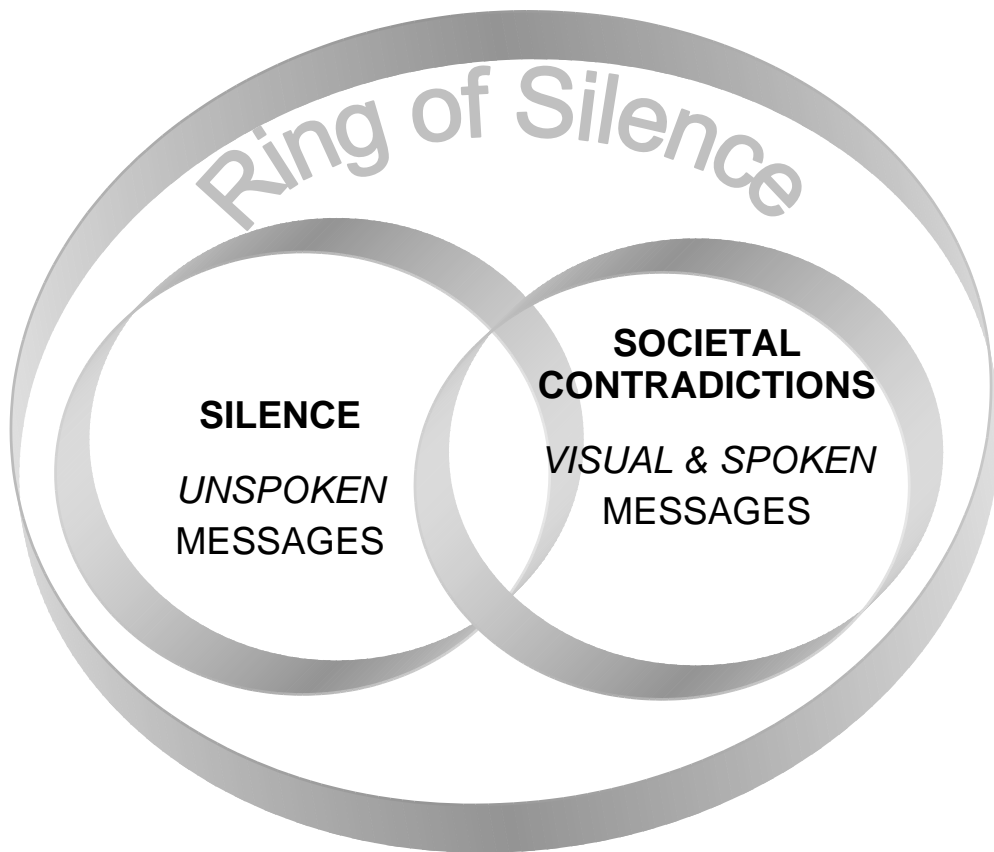
Twentieth century anthropologist, Margaret Mead's study of various cultures led her to conclude, "Breasts are so idealized in America that they are the primary source of female identity" (Mead, 1949 in U.S. DHHS, 1984, p. 108). Many women who have survived breast cancer admitted to a delay in getting mammograms or having follow-up examinations for fear of losing their breasts. The message about women's breasts in advertising and culture has been extremely powerful. In addition, women themselves have treated breasts as ornaments. Depending on the fashion of the day, breasts have been padded, bound, and pumped up with silicone or saline. Many women who lose a breast

feel a loss of identity and self-worth because of these social expectations (Rosenbaum & Roos, 2000).

Integrative Theme: Ring of Silence

The integrative theme, *ring of silence* describes the central theme that emerged from the data in connection with the participants' experiences and perceptions of significant events related to experiences concerning their breasts. *Ring of silence* (Figure 2) conveys the intertwined and contradictory messages, both spoken and unspoken, that women receive from multiple sources. The term *integrative* was selected to describe this theme rather than overarching, interpretive, or another similar term because there was some overlap in the examples obtained from the data to describe data that could be applied to more than one thread that ran throughout the women's stories. The term *womanhood* had two meanings for these participants and was paradoxical, creating a lifelong, often unrecognized, intellectual, and emotional m el e. As one participant stated, "I would say that it is like there are two people inside me that do battle around that [womanhood]." Participants defined the term *womanhood* as the strong, nurturing attributes of women, embodied in spirituality and femininity, while at the same time acknowledging that society defines women by particular body measurements. The participants recognized that society, through messages communicated in the media and the advertising industry, have "conditioned" women to believe that having large breasts is a sign of womanhood. The contradictions between societal expectations of women and womanhood, based on the size and shape of women's breasts, were revealed in the narratives as the women shared their personal and, at times, conflicting definitions of the term womanhood. Silence and conflicting messages from society have, for the participants in this study, created conflicting definitions of African American women's identities.

Figure 2. A visual representation of the integrative theme: Ring of silence.



The theme *Ring of silence* is an integrative theme that implies a semblance of silence. The word *ring*, in addition to being defined as a small circular band of metal, an outer edge of something circular, an enclosed area or a group of people working together to advance their own interests, as a noun is also defined as the characteristic sound, a semblance, or impression of some feeling (Webster's New World Dictionary & Thesaurus, 2003). Another definition of the word *ring* is to convey a specified impression or feeling (Webster's New World Dictionary & Thesaurus, 2003). Finally, the fundamental definition of *ring* is a clear, resonant sound, whereas *silence* is defined as the absence of sound (Abate, 1997). The term *ring* in this sense does not refer to an audible sound, a tangible circular figure, or article of jewelry, but is used to portray the semblance, pretense, façade, or impression of silence and stillness as expressed in the narratives shared by the participants in this study.

The messages that these participants perceived regarding women's breasts were often unspoken yet were loud and clear. For example, participants shared stories of padding their bras to impress boys or men and feelings of shame related to their breast size because of the "whispers." Not only was the size of women's breasts important to these women, but also the shape and appearance of their breasts in relation to images displayed in the media were significant. One participant shared feelings of guilt "to this day" because of her inability to breast-feed her children. Women shared their feelings of insecurity because of the physical changes that occur with the aging process. For example, as one participant shared, "I used to walk around the house without a top on; now I put on a bra and cover up, so that it doesn't appear to my husband that I have a flat chest." Health care professionals and the health care system, in general, may have perpetuated women's feelings of insecurity by not preparing them in advance for screening procedures, such as the mammogram. According to the participants, providers often do not take the time to "talk" with their clients/patients before or after medical procedures. This often left the women feeling inadequate or ashamed.

According to Ferguson and Kasper (2000), "From her earliest years, most girls identify with what it means to be female, and numerous messages suggest how she should view herself and how society will view her" (p.3). Society has attached multiple meanings to being female, including the expectation that a woman should be physically and sexually attractive, and maternal. The breasts, more than any other female body part, plays a significant role in these expectations. It was not long ago when social norms mandated that women's breasts should not be discussed publicly, and the experience of breast cancer was silenced and viewed as a private matter.

Silence is far more than not speaking: Silence itself is a form of speech. The integrative theme, *Ring of silence*, "rings" with layers of meaning. Silence for these women have created untenable perceptions of breast cancer risks and cancer in general, and may have influenced these women's attitudes regarding breast cancer screening.

Limitations and Strengths

It is possible that I contributed some influence about what the women chose to write in their narratives by providing a list of topics to help trigger memories of times in their lives, when experiences concerning their breasts may have been especially important to them. I also acknowledge that because I belong to the same racial and

socioeconomic group as the study participants, the researcher's presence may be perceived as a limitation.

A feminist perspective holds that all human experience is gendered experience, and women's stories are rarely told without reference to the dynamics of gender (Personal Narrative Group, 1989). "Issues in equity, power, social structure, agency and self-definition are brought to light by the writing of all kinds of personal narratives, of all kinds of lives, of all kinds of women" (Smith, 1994, p. 299). Women experience patriarchy in unique ways, multiple truths exist, and experiences reflected in the narratives may change with time, and current experiences may change perceptions. The participants were candid, seemingly honest, and excited to share their stories. I have no reason to believe that the information and experiences shared are less than congruent with the women's memories of their past experiences.

Conclusions

Additional studies with a larger sample of women from a variety of racial/ethnic groups are needed to fully address the question, "Is there an association between women's past experiences and their current breast cancer screening behaviors?" Although this study did not fully explain women's current breast cancer screening behaviors in relation to their experiences, some of the participants did share examples that strongly suggest there is a relationship. For example, one participant stated,

My first bra brought with it some mixed emotions. I wanted to pay no attention or make any mention of my breasts. Consequently, this reluctance caused me to delay my first mammogram when I thought I felt a lump in my breast when I was in my mid-30s.

What this study accomplished was to empower women to speak out about what is important and significant to them. Another goal was that women would gain insight concerning feelings about their breasts with regard to breast cancer screening through personal reflection, as they discussed their experiences. This inquiry revealed both the spoken and unspoken social and patriarchal issues that have oppressed women for many years, and enabled the participants to become more cognizant of their own strengths and abilities to find ways to break the "conspiracy of silence." During the follow-up interviews, a majority of the participants voiced the need to encourage women to be more vocal concerning their needs. One participant stated,

We need to educate the public and encourage women to be more vocal about their needs. I just want to encourage women to be up front, truthful, and as vocal as they need to be to get what they need. Don't be afraid to ask.

The study provided an opportunity for the women, in their own way, to start a new cycle of breaking the silence that may be associated with self-image and health promotion behaviors related to breast cancer screening. One participant, in particular,

gave voice to the message that a majority of the participants attempted to convey in their narratives when she stated,

I think as we begin to talk, each generation will become more educated about these things [breast cancer screening]. I think African Americans will become aware just from their parents teaching them and seeing their parents go in for mammograms.

Although the literature on ethnic minority women's breast cancer screening behaviors is substantial, researchers have not explored women's past experiences across the life span in relation to their breasts and their current breast cancer screening behaviors. Other than one study concerning links between prior experience, thinking, and emotion in young children (Lagattuta & Wellman, 2001), researchers have not explored possible associations between prior experiences related to women's breasts and women's current breast cancer screening behaviors. One other study, not related to breast cancer screening behaviors, showed that patients sometimes make decisions based on intuitive feelings that are affected by emotions related to memories about events that occurred in the past (Redelmeier, Rozin, & Kahneman, 1993). In addition, previous studies related to breast cancer screening behaviors of ethnic minority women have focused primarily on socioeconomic factors or on women who have been diagnosed with breast cancer. Although socioeconomic factors have been shown to influence the stage of disease presentation and to explain some of the racial disparities in breast cancer mortality, socioeconomic factors only partially explain this disparity.

The theme *Ring of silence* conveys the intertwined and contradictory spoken and unspoken messages that women receive from multiple sources and their perceptions because of these messages. For the participants in this study, these contradictions may serve as barriers to breast cancer screening. Health care professionals and the health care system in general may inadvertently perpetuate women's feelings of insecurity, by not preparing them for screening procedures, such as the mammogram, in advance. According to the participants, providers often do not take the time to "talk" with their clients before or after medical procedures. This left the women feeling inadequate or ashamed. Because of the silence these participants experienced, many of the women formed perceptions regarding breast cancer screening and cancer in general based on inaccurate information from their peers or misinterpreted information. One participant captured the impact of silence and the conflicts that arise, or the resultant perceptions of shame, when she stated, "The silence is a conspiracy that has hurt us for generations." Silence is something that society in general has used and continues to use powerfully. As an initial step in erasing our society's definition of womanhood and eliminating the "conspiracy of silence," several of the participants suggested the encouragement of multigenerational dialogue. This step alone can empower women of all ages to recognize that individual women are capable of defining themselves and may ultimately have a positive outcome on minority women's breast cancer screening behaviors. In addition, a definition of womanhood is needed that does not primarily focus on physical attributes but includes all aspects of being human.

Nine participants reported having a mammogram within the past 2 years, and 4 women reported doing monthly BSEs on a regular basis. One participant had never had a

mammogram. She explained, "I guess I have just never given it much thought in its [mammogram] relationship with me. I truly have no idea why it has not been a top priority on my list of preventative health care practices."

Ten of the 12 participants reported that their first mammogram was a very negative experience, an experience they "would never want to repeat." Statements describing their first mammogram experiences included, "I had no idea what to expect," "The pain was terrible," and "It hurt like HELL!" "She grabbed one of my breasts and placed it on a COLD-COLD table," and "It was so cold." The participants were not only describing the temperature of the examining room and equipment as being cold, but also the perceived attitudes of the health care providers and technicians. For instance, as one participant shared, "I hate breast exams. They are so painful and the nurses are so impersonal."

Another participant expressed her discomfort with the examination saying

My first experience in having a mammogram was so scary and humiliating. He [the doctor] was rather nonchalant. The technician came over and said, "You really don't have much at all." The experience only heightened my shame [of having small breasts] from earlier years. The technician was not gentle, was not nice, and it was very embarrassing.

Findings (related to the participants' first mammogram experience) include the experience of pain from the mammogram procedure itself, embarrassment, feelings of humiliation, and perceptions of going in "cold turkey" because "no one told me what to expect."

Additional studies such as this may reveal life experiences that could have an impact on women's breast cancer screening behaviors. This study was useful in gaining additional insights that could lead to the development and implementation of breast cancer screening programs that meet the needs of African American women and possibly transcend ethnic/racial and cultural boundaries in future health promotion efforts related to breast cancer screening. One approach might be to have mother and daughter health education classes in schools. One participant explained,

There was never an ongoing dialogue with my mother about personal things, and I did not feel free to ask her anything. Neither my mother nor any of the other parents that I knew of talked about those things during that time.

Participants emphasized the need for earlier breast health education and suggested that educators incorporate breast health and cancer screening in current sexuality and health education classes in schools. Researchers time and again suggest that mothers are the primary source of sexuality information in African American communities, and that the mother-daughter relationship is essential to exploring issues related to adolescent body image and self esteem (Royce & Balk, 1997). However, other researchers suggest that "many mothers may be ill-prepared to teach their children about sex" (Hockenberry-Eaton, Richman, Dilorio, Rivero, & Maibach, 1996, p. 35) or reinforce information they learn in school. This suggests a need to develop breast and other health education classes

for mothers and daughters. As one participant explained, “We need to talk about body changes before it happens, way before that. We need to talk about it like it is a normal body thing, which it is. It doesn’t have to be taboo.”

Health care practitioners and educators can help break the “conspiracy of silence” by discussing with female students and patients about where their personal ideal self-image comes from, both the pros and the cons. In turn, female nurses may then become more open to discussing self-image with their clients, and consider the probable impact of self-image on women’s health behaviors. In addition, health educators can challenge students to review current health behavior models for appropriateness rather than accepting current models as being suitable for addressing specific issues pertaining to the health behaviors of ethnic/minority groups.

Both health educators and practitioners should consider encouraging women from all ethnic/racial and cultural groups, to examine where their expectations for self come from, thereby allowing women the freedom to sort out their own beliefs and feelings about their breasts and their bodies rather than making decisions based on the values defined by society.

This inquiry illuminates the significance of women’s past experiences and feelings about a phenomenon, women’s breasts, which a few years ago was taboo to discuss openly and, in some settings, continues to remain taboo (i.e., in certain religious denominations). In the dialogue about women’s breasts, breast cancer, and cancer screening behaviors equal weight has not been given to everyone’s story because the narratives of minority women often have not been heard. An awareness of women’s memories and feelings related to their breasts or past breast cancer screening experiences is critical to understanding the breast cancer screening behaviors of African American women and women in general.

“A woman’s definition of self is based on a lifetime of feedback about having breasts, menstruating, and being able to engage comfortably in sexual activity. Breast cancer threatens this self-perception” (Wilmoth, 2001, p. 283). For the most part, the participants agreed that the messages from society play a significant role in women’s self-identity. Another participant explained, “Society wants you to believe that it [womanhood] is defined by certain bodily measurements, but no, it [womanhood] is learned behavior and it [womanhood] is a conditioned response to how you view yourself.”

Health care professionals and women in general may not be aware of the influence that memories and the accompanying feelings or perceptions about oneself may have on current health behaviors. The narratives provided valuable information for health care professionals, policy makers, ethnic minority women in general, and other community leaders who may have the power to effect change in minority cancer screening behaviors and cancer outcomes. It is anticipated that this study and future studies that explore women’s stories concerning specific life events will result in a more in-depth understanding of factors that have an impact on women’s cancer screening and health promotion behaviors in general. Knowledge gained from this study will provide health care professionals with fresh perspectives about covert influences on mammography screening behaviors, increase our understanding of barriers to mammography screening that have not been identified in other studies, and provide new insights for developing culturally relevant mammography screening interventions.

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Author Note

Dr. Thomas has been involved in all levels of nursing since the late 1960's and recently earned her doctorate degree from the University of Colorado, Health Sciences Center, School of Nursing. She is currently an assistant professor in the College of Nursing at the University of New Mexico. She has been very involved in community health nursing and her research interest is focused on health disparities and minority women's health promotion and cancer screening behaviors. In particular, Dr. Thomas is interested in exploring the impact of women's experiences on their current health promotion behaviors related to mammography screening. In collaboration with UNM College of Nursing and Cancer Research and Treatment Center, New Mexico Department of Health Early Detection Program, New Mexico Primary Care Associates, and New

Mexico American Cancer Society, she is spearheading efforts to obtain funding for a Women's Mobile Health Unit that will be used to reach women in rural areas of New Mexico. Not only will this mobile unit provide access to cancer screening for women in rural areas but will serve as a multidisciplinary teaching and data collection site for students and faculty on the Health Sciences Center campus of UNM. Because of her work with health disparities and minority health research, she was named a Health Disparities Scholar by the National Institutes of Health National Center on Minority Health and Health Disparities.

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