Understanding Perceptions of Breast Health in a Southern Appalachian Community

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Dedication

To my mother, Diane, and to my entire family. Your unwavering love and support mean everything to me.

To my beloved MK. Thank you for being you.

To the memory of Melissa B. Sult, a beautiful friend who will never be forgotten.

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Abstract

Culture is central to how individuals perceive and understand health. Thus, the Appalachian culture impacts how Appalachian women perceive and maintain breast health. Using information about the broader Appalachian region and the Southern Appalachian sub-region, specifically, as well as the existing body of literature about cancer, culture, and communication theory, this qualitative study describes breast health from the point of view of women and health information providers in this region in order to better communicate about breast health maintenance practices.

Results from this study will allow individuals working with breast cancer patients and prevention to better understand how cultural identity influences perceptions related to breast health, as well as develop more culturally appropriate breast health messages, which may reduce breast cancer mortality in the long term.

Qualitative in-depth interviews were conducted with 32 women and 4 health information providers in one Southern Appalachian community. The main theme that emerged from the data was: Appalachian Cultural Identity Moderates Perceptions About Breast Health. Four thematic constructs helped support the main theme: (1) The belief that breast health maintenance through recommended practices is important, (2) The belief that personal relationships impact breast health positively, (3) The belief that culture impacts breast health negatively, and (4) The belief that circumstance impacts breast health negatively.

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Chapter 1

INTRODUCTION

The Appalachian region of the United States extends south from southern New York nearly 1,000 miles into Tennessee, Georgia and Alabama. This region includes 420 counties in portions of 13 states, including all of West Virginia, and is home to approximately 24.8 million people (Appalachian Regional Commission, n.d.a). The Appalachian region is further divided into three parts: the Northern, Central and Southern Appalachian sub-regions. From a health communication perspective, little is known about the Southern Appalachian region; however, previous research indicates that the Appalachian population differs greatly from other rural populations in terms of health (Cavender, 1996; Hutson, Dorgan, Phillips, & Behringer, 2007). States with counties in the Appalachian region tend to have worse overall health than their non-Appalachian counterparts. For overall health ranking in 2010, nine of the thirteen Appalachian states fell in the bottom 20 (United Health Foundation, 2010).

Cancer in the Appalachian Region

One area of health that is particularly troubling in the Appalachian region is the high rates of both incidence and mortality for all types of cancer. Across the board, these rates are higher in the Appalachian region than the US averages (Huang, et al., 2002). Research also suggests that Appalachians are more likely to be diagnosed in a later stage of cancer, and that their knowledge of risk reduction and screening methods is low (Shell, et al., 2004). Additionally, there is evidence to support that Appalachians do not use traditional healthcare providers (i.e. doctors, nurses, etc.) as primary sources of cancer

information. Cavender (1996) explored the long history of "unorthodox healers," ranging from faith healers who use the power of faith to treat the ill to medicine men who use natural elements, such as herbs, to combat sickness, in the Appalachian area. The area's history with non-traditional medicine has possibly influenced the attitudes Appalachians have about medicine today. Bettencourt, Schlegel, Talley, and Molix (2007) found that rural and Appalachian women were often reluctant to discuss their breast health with a doctor because they often felt that doctors did not listen to their concerns, did not treat them with respect, and/or felt the doctor could not be trusted. Finally, Shell et al. (2004) conducted nine focus groups about cancer in the Appalachian area and found that many individuals simply do not seek treatment from a doctor, especially if cancer is suspected, because they believe that if they do have cancer, nothing can be done to treat it.

Cancer in the Southern Appalachian Sub-region

As unsettling as cancer is for the Appalachian region in general, the cancer-related challenges faced in the Southern sub-region of Appalachia are greater than those in both the Central and Northern sub-regions (Wingo, et al., 2007). Reports about cancer incidence and mortality rates in the Southern Appalachian sub-region vary according to source, with some sources estimating that cancer rates are lower in the Southern Appalachian sub-region (i.e. Appalachian Regional Commission, n.d.a). Other sources estimate that both cancer incidence and mortality rates in the Southern Appalachian sub-region are much higher than those reported due to inadequate surveillance systems and reporting procedures (Wingo, et al., 2007). For both the Appalachian region in general

and the Southern sub-region specifically, the four most prevalent types of cancer are lung, prostate, breast and colorectal (Wingo, et al., 2007).

Breast Cancer in Southern Appalachia

The most common type of cancer for women in all demographic groups, both Appalachian and non-Appalachian, is breast cancer. While it is possible for men to get breast cancer, women account for 99% of all breast cancer cases (Susan G. Komen for the Cure [SGK], 2009). Incidence rates for breast cancer in the Southern Appalachian sub-region are slightly lower than those in non-Appalachian areas (117/100,000 vs. 120/100,000); however, both incidence and mortality rates in some counties are markedly higher than the national mortality rate for breast cancer (Wingo, et al., 2007). In Claiborne County, Tennessee, the county included in this study, the incidence rate for breast cancer among white females is 131/100,000 and the mortality rate is 41/100,000, compared to 24/100,000 in the United States overall (Tennessee Department of Health, 2008). The high incidence and mortality rates for breast cancer in this area have made the author wonder what influences breast health in this area and how that information can be used to develop more culturally appropriate theories for communicating about breast health in the Appalachian region.

Purpose and Research Question

The purpose of this study is to better understand the relationship between culture and attitudes toward health and to use communication theory to better explain how breast health is understood and maintained in the Appalachian region. Using information about the broader Appalachian region and the Southern Appalachian sub-region, specifically, as

well as the existing body of literature about cancer, culture, and communication theory, the researcher intends to understand breast health from the point of view of women and health information providers in this region in order to better communicate about breast health maintenance practices. Results from this study will allow individuals working with breast cancer in Appalachian communities to better understand perceptions related to breast health from the community's perspective as well as develop more culturally-appropriate breast health messages, which may reduce breast cancer mortality in the long term. Qualitative in-depth interviews were used to explore breast health in one Southern Appalachian county. Long interviews allowed women and health information providers to describe their perceptions of breast health in their own words. Using the constant comparative method, themes were generated, as theoretical concepts were "grounded" in the data and use characteristic examples from the data to present the phenomenon (Glaser & Strauss, 1967). Additionally, findings will be related back to existing literature about cancer, culture, and health communication theory. The following research questions guide the study: How do women and health information providers in one Southern Appalachian community perceive issues surrounding breast health? How does culture affect these perceptions?

Chapter 2

LITERATURE REVIEW

This qualitative study seeks to understand how women and health information providers in Southern Appalachian communities define breast health. Unlike in more positivistic inquiry, review of relevant literature in qualitative inquiry is most often used in the analysis and discussion portions of the report to help explain and situate research findings (Corbin & Strauss, 2008; Glaser & Strauss, 1967). While existing literature does not guide the research process in qualitative inquiry, there are several advantages to reviewing relevant literature prior to collecting data. First, the literature review can make the researcher more sensitive to subtle nuances during the data collection process. Also, the literature review can suggest questions for initial observations and interviews (Corbin & Strauss, 2008). The following section presents relevant literature related to health, culture, communication, social determinants of health and relationships to traditional healthcare. The following topics are examined: (1) culture and health in Southern Appalachia, (2) Appalachia and the social determinants of health, (3) the role of traditional healthcare in Appalachian health, (4) media use in Appalachia, and (5) how health communication theory has been used previously to explore health in the Appalachian region.

Culture and Health in Southern Appalachia

Culture is "the core, fundamental, dynamic, responsive, adaptive, and relatively coherent organizing system of life designed to ensure the survival and well-being of its members and is shared always to find meaning and purpose throughout life and to

communicate caring" (Kagawa-Singer, Dadia, Yu, & Surbone, 2005, p. 17). Culture is recognized as one of the most important factors in health (Ali, Atkin, & Neal, 2006; Kreuter & McClure, 2004; Papadopoulos & Lees, 2004); however, the Institute of Medicine (2002) points out that culture is rarely explored beyond surface cultural factors, such as race, education level and socioeconomic status. Resnicow and Braithwaite (2001) argue that it is equally, if not more, important to address deeper cultural structures that affect health, such as social, psychological, environmental and historical factors.

The Appalachian region is well known for its time-honored cultural traditions, such as the importance of family ties, faith in God, and widespread tobacco use (Katz, Wewers, Single, & Paskett, 2007). Behringer, et al. (2007) found several cultural characteristics unique to the Appalachian region. First, they and other researchers have reported that individuals in Appalachia feel both geographically and culturally isolated, and that they are invisible to institutions, such as government and healthcare (Katz, et al., 2007; Schoenberg, Hopenhayn, Christian, Knight, & Rubio, 2006). Geographic isolation refers to the fact that the Appalachian region is a mountainous one, and many communities are located well away from large, metropolitan areas and major highway systems. This type of isolation has several implications for health. Hutson, et al. (2007) conducted focus groups with informal community leaders in the Appalachian area and found that because Appalachian communities are geographically remote, they are often misunderstood or unfairly stereotyped. As one participant noted, "People come in here from Washington or places and they don't see the good things about the area. They mostly pick out the poverty and language and the fact that we are coal mining and how

bad it looks in places…that's all that people see about our area" (Hutson, et al., 2007, p. 1136). As a result, social policies around issues like health may be lacking the Appalachian voice and, ultimately, not meet the area's needs. Geographic isolation may also lead to less interaction with healthcare professionals and, as a result, less exposure to messages of prevention and early detection that may reduce cancer mortality rates. Behringer, et al. (2007) formed two Appalachian community-based cancer research review work groups through a five-year, grant-funded project to explore lay interpretations of cancer research findings. The study determined that geographic remoteness affected health in that transportation to healthcare facilities can often be problematic. Katz, et al. (2007) also explored transportation issues when they interviewed key informants from Appalachian communities in Ohio. Participants pointed out that while a healthcare facility may be close by, it may not be adequate for the kind of treatment needed. Especially in the case of cancer treatment, where specialist care is almost always needed, access to a technologically advanced treatment facility can be critical to a patient's outcome. Bettencourt, et al. (2007) reviewed 41 studies regarding the breast cancer experiences of rural women. An overarching theme from this meta-analysis was that proximity to a state-of the-art treatment center greatly increased the likelihood of a positive outcome with regard to breast cancer. The existing literature clearly supports the idea that the geographic isolation of many Appalachian communities does impact health, but geographic is not the only type of isolation prevalent in the Appalachian area.

In many ways, the Appalachian region is also culturally isolated, which refers to the "suspicion of "outsiders" [that] may have been passed down through the generations, possibly resulting in families and communities tightening their loyalties to in-group members (and becoming more suspicious of out-group members)" (Behringer, et al., 2007, p. 44). Just as geographic isolation can negatively impact health, so too can cultural isolation. Ludke, Obermiller, Jacobson, Shaw, and Wells (2006) conducted interviews with 75 self-identified Appalachian adults in Ohio and found that low health literacy and inadequate coping strategies were two results of cultural isolation. As noted above, individuals in the Appalachian area are less likely to travel for medical care due to transportation constraints, but when they do, they may have difficulty understanding and remembering what the doctor said (Ludke, et al., 2006). A solution to this problem may be apparent in bringing more medical resources into an Appalachian community; however, help from sources outside the community may be rejected due to the suspicion of outsiders (Behringer, et al., 2007). In their study of community-based work groups, Behringer, et al. (2007) found that outside programs and resources might be rejected by Appalachian communities because residents fear that they will be stereotyped as "uneducated hillbill[ies]" (p. 45) and that information from outside sources is often not accessible for these communities. Because culture is an important part of health, it is not enough to simply transfer a program from one area to another without making cultural adjustments (Behringer, et al., 2007).

Another cultural aspect of Appalachia that may influence individuals' perceptions and understanding of cancer is the "strong regional faith in God" (Behringer, et al., 2007,

p. 44). Faith is a term "often used interchangeably with religion and spirituality" (Diddle & Denham, 2010) and refers to an individual's belief in a "presence that is higher or greater than the individual human being" (p. 175). In their study with community-based work groups, Behringer, et al. (2007) found that health professionals and, subsequently, health messages that "acknowledge this faith as part of a rural Appalachian's life and philosophy may be better received by the larger community and the patient base" (p. 44). Diddle and Denham (2010) conducted a review of literature pertaining to health, spirituality and faith in Appalachia and found that both belief in God and the Bible have been "enduring resource[s] during times of trouble and hardship" for Appalachians, which is one explanation for why reliance on faith is often cited as a way to understand and/or cope with health problems, such as cancer (p. 176). Keefe and Greene (2005) explored religious and spiritual beliefs in terms of their relationship to mental health treatment and found that many Appalachian's believe that illness is a direct result of God's will or offending God. In a study examining the relationship between faith and physical health, Powell, Shahabi, and Thorensen (2003) found nine overarching beliefs about the power of faith. Among these nine were the beliefs that attending church and/or faith protects against death generally, protects against death from cancer and other chronic illnesses (such as heart disease), slows the progression of cancer and that individuals who use faith as a coping mechanism during times of hardship will live longer. Simpson and King (1999) studied health-related activities within religion-community partnerships in Appalachia and found that activities both within religious services and between religious groups and the community were ways to incorporate faith

into the process of treatment and healing. During religious services, individuals may request prayer for themselves or another member of the community to expedite healing. In some cases, individuals may ask to be anointed, where s/he is prayed over by a pastor or church elders, usually while those praying are touching the person requesting prayer (Simpson & King, 1999). Within the broader community, churches or other religious groups may sponsor programs or other outreach activities centered around specific health problems (Simpson & King, 1999). Diddle and Denham (2010) acknowledge the lack of overwhelming support for the link between faith and health in Appalachia, but do concede that the existing literature supports "a limited but encouraging relationship" between the two (p. 179).

Finally, the widespread use of tobacco cannot be overlooked when discussing cancer in the Appalachian region. With its long tradition as a tobacco-growing region, it is not difficult to understand why tobacco is considered part of the culture in Appalachia. Tobacco use is highest in the Appalachian region in terms of both smoking and smokeless tobacco (United Health Foundation, 2010). Rates of cigarettes smoking within Appalachia range from 16% on the low end (in Maryland, New York and Georgia) to more than 25% on the high end (in Kentucky and West Virginia) (Centers for Disease Control [CDC], 2009a). In 11 of the 13 Appalachian states, rates for other tobacco use are moderately high (1.5%-3%) or high (greater than 3%) (CDC, 2007). Ahijevych, et al. (2003) found that individuals in the Appalachian region did not view cigarette smoking as harmful to health, but as unrelated to other health problems. One participant stated, "I know people who smoked all their life and had a stroke. Cigarettes didn't cause that" (p.

98). Additionally, smoking was seen to have some positive effects that mitigate the negative effects, such as aiding in losing weight (Ahijevych, et al., 2003). In addition to increasing the risk of all types of cancer, smoking also increases the risk for cardiovascular disease, heart attack and stroke (CDC, 2009b).

Because tobacco use is so prevalent in Appalachia, it is not surprising that the rates for other tobacco-related illnesses are also high (United Health Foundation, 2010). Appendix A summarizes the health rankings of Appalachian states for tobacco-related illnesses (cancer, heart disease, heart attack, and stroke). As Appendix A indicates, the prevalence of tobacco use, specifically smoking, is indicative of how well or poorly a state is ranked on these measures.

In addition to tobacco-related illnesses, the prevalence of obesity and diabetes are also concerns in Appalachia. Obesity, which is defined as having a Body Mass Index (BMI) of 30 or greater, increases the risk for heart disease, diabetes, cancer (especially endometrial, breast and colon), heart attack and stroke, among other health problems (CDC, 2011). Appendix B summarizes the health rankings of Appalachian states for obesity and diabetes. Health rankings and epidemiological data are not the only factors to consider about health in Appalachia. It is equally important to consider how particular social factors affect health.

Appalachia and the Social Determinants of Health

Poverty is one of the greatest predictors of poor health status (Erwin, 2008). Given the previous description of the poor health burden in Appalachia, it is not surprising that the Appalachian region “remains a symbol for poverty and

underdevelopment" (Thorne, Tickamyer, & Thorne, 2005, p. 341). According to the Appalachian Regional Commission (n. d.c), 82 of the 420 counties in the Appalachian region are categorized as economically distressed in 2011. A county qualifies as economically distressed if its median family income is no greater than 67% of the national average and its poverty rate is 150% of the national average or greater (Appalachian Regional Commission, n.d.b). In 2011, this means that the median family income within a county can be no more than $42,455 (US Census Bureau, 2011b) and that individual families must make $33,525 or less (based on guidelines for a family of four) (US Department of Health & Human Services, 2011). Additionally, rates of both unemployment and poverty in the Appalachian region are above the US averages. The poverty rate in Appalachia is 18% (Appalachian Regional Commission, n.d.d) compared with the national average of 14.3% (US Census Bureau, 2011a). Both unemployment and poverty limit the ability of an individual to access and participate in healthcare in a number of ways, even without added cultural barriers (Bartley, Ferrie, & Montgomery, 2006). Unemployed individuals are less likely to have health insurance and, therefore, access to traditional healthcare providers (i.e. primary care physician, etc.) (Thorne, et al., 2005). Unemployment and poverty may also restrict and individuals ability to travel to a healthcare facility. This is especially important in the Appalachian region where there are few major healthcare facilities in nonmetropolitan areas (Hall, Uhler, Coughlin, & Miller, 2002). In terms of cancer screening and treatment, access to these types of facilities may be required.

Education level is another determinant of health status, but it is linked to both poverty and access to health care. Individuals who are more educated tend to have better overall health status (United Health Foundation, 2009). Education is also linked to poverty in that individuals with more education are less likely to live in poverty because they are more likely to have a job that offers health insurance coverage (Thorne, et al., 2005), which increases their access to care. In addition to general education, adequate health education is also needed to reduce rates of cancer in Southern Appalachia. Previous studies have highlighted the instrumental role of health education in increasing awareness about health in general and breast health specifically (Canales & Wilkinson, 2002; Haas, et al., 2005; Leslie, et al., 2003).

The Role of Traditional Healthcare in Appalachian Health

Unlike their non-Appalachian rural counterparts, individuals in Southern Appalachia do not consider traditional healthcare providers (i.e. doctors and nurses) the most trusted sources of health information (Hutson, et al., 2007; McMillan, et al., 2007). Previous research has found that individuals in the Appalachian region feel that visiting the doctor is asking for trouble (Hutson, et al., 2007) or to be "taken advantage of" by the healthcare system (Behringer, et al., 2007). Additionally, individuals in the Appalachian region expect poor outcomes from interactions with healthcare professionals, especially when it comes to cancer (Behringer, et al., 2007). For example, Hutson, et al. (2007) found that individuals in Appalachia viewed cancer as "inevitable" since many people both get and die from cancer in this area.

One explanation that has been offered for this mistrust of health professionals is the inability of individuals in Appalachia to adequately cope with interacting with a health professional, particularly if the individual must travel to a more metropolitan area for care (Ludke, et al., 2006). In terms of cancer, living in Appalachia has been described as a "place-based disparity," (Behringer, et al., 2007) which means that individuals will likely have to travel to receive any type of specialized care. Appalachian populations have cited fears of being stereotyped as an "uneducated hillbilly" as a reason for not trusting medical professionals as well (Behringer, et al., 2007, p. 45).

Due to the overwhelming mistrust of health professionals, individuals in the Appalachian region are more likely to value to health information from family, friends and neighbors as well as turn to other nontraditional sources for both health information and treatment (Cavender, 1996; Harris & Wathen, 2007). By avoiding mainstream sources of health information, individuals in Appalachia are placing themselves at risk to receive false or potentially dangerous information about health in general and breast health specifically (Bettencourt, et al., 2007). It is important to explore the range of nontraditional sources and channels of breast health information to better understand how they shape the definition of breast health in the Southern Appalachian region.

Media Use in Appalachia

Another important factor to consider is the type of media most commonly used in the Appalachian area. Understanding the types and ways media are used directly affects the type of information to which an individual is exposed.

Vanderpool, Huang, and Shelton (2007) reviewed data from the Health Information National Trends Survey (HINTS) and found that individuals in Appalachia were less likely to go online than their non-Appalachian counterparts. Additionally, Appalachians were more likely to connect to the Internet using telephone modems (dial-up) rather than broadband. In a USDA report, Stenberg, Morehart, and Cromartie (2008) explained the challenges of expanding broadband use to areas such as the Appalachian region. Broadband is less common in these areas because it is expensive to set up due to sparse populations (people are spread out over a large geographic area rather than clustered in a small area) and difficult, mountainous terrain.

McNeill and Dorgan (2004) interviewed 88 Appalachian women via telephone about mass media messages related to breast cancer screening behavior. The study found that while the women in the study recalled information from mass media campaigns, they were only likely to act on it if it aligned with information they received from family and friends. These results indicate that while mass media campaigns can raise awareness about cancer risks, the behavior of Appalachian women is much more likely to be influenced by their family and friends. In their review of a CDC mass media program aimed at increasing screening for colorectal cancer, Vanderpool and Coyne (2006) discussed problems related to implementing these types of programs in the Appalachian region. First, these programs are likely to be implemented at the state or regional level, which means the materials often do not make it into more rural areas of the state. Health information providers interviewed for the study preferred that program materials be made available at the local level to increase implementation in rural areas. The study also found

that not all materials were well tailored to Appalachian populations. For example, one participant said that one brochure among the program materials was particularly useful because it was written for low-literacy individuals. Finally, while the program increased awareness of screening programs, it wasn't linked to increases in screening behavior. In a study that assessed knowledge of breast and cervical cancer among Appalachian women, Lyttle and and Stadelman (2006) found one final problem with using mass media messages in this region: Appalachian women do not respond well to mass media messages from strangers, which further underscores the need to make programs more locally focused.

Using Communication Theory to Understand Health

Freimuth and Quinn (2004) describe four ways that health communication theory can be used to understand how health information is shared: entertainment-education, media advocacy, interactive health communication, and interpersonal communication, which includes patient-provider communication.

Entertainment-education uses popular media, such as television programming, to disseminate important information about particular topics, in this case, health (Freimuth & Quinn, 2004). The entertainment-education strategy has been identified as useful among populations that experience health disparities, especially women (Hether, Huang, Beck, Murphy, & Valente, 2008; Wilkin, et al., 2007; Wilson & Beck, 2002). For example, the popular HBO series *Sex and the City* used education-entertainment when one of its main characters, Samantha, experienced breast cancer. There has been limited exploration in the literature of the use of entertainment-education in the Appalachian

region (Wright, 2009), but is likely to have utility as other narrative strategies, such as storytelling, have been used successfully in this area (Fisher, 1993; Kerney, 2000; Lee, Ozanne, & Hill, 1999).

In addition to entertainment-education, media advocacy, which includes social marketing, is also a useful way to communicate about health (Dorfman, 2003; Wallack, Dorfman, Jernigan, & Themba, 1993). According to the Institute of Medicine (2003), media advocacy is "the strategic use of mass media and their tools, in combination with community organizing, for the purpose of advancing healthy public policies" (p. 338). Media advocacy has been used to address a number of health issues, including cardiovascular disease (Schooler, Sundar, & Flora, 1996), tobacco control (Wallack, 1994), diabetes (Gollust & Lantz, 2009), and cancer (Brown, Zavestoski, McCormick, Mandelbaum, & Luebke, 2002; Schwartz & Woloshin, 2002; Stryker, Solky, & Emmons, 2005). In terms of impact on breast health, Jones, Denham, & Springston (2006) found that the media has a significant positive impact on breast cancer screening, especially among middle-aged women. Much of the existing literature regarding media advocacy in Appalachia has focused on tobacco control initiatives and interventions (Horn, Dino, Kalsekar, & Fernandes, 2004; Toborg, Meyer, & Mande, 1997; Wewers, Ferketich, Harness, & Paskett, 2009).

Interactive health communication tools, such as telemedicine and computer-mediated health communication, have been touted as ways to increase medical care for rural and other underserved populations (Graham, 1996; Neuhauser & Kreps, 2003; Patrick, 1999; Raza, Joshi, Schapira, & Agha, 2009; West, Lagua, Trief, Izquierdo, &

Weinstock, 2010). Fotheringham and Owen (2000) point out that interactive health communication initiatives demand "substantial investment in hardware, software, and the time needed to produce high-quality work" (p. 112). For communities that are not already equipped to integrate such interventions, the cost of preparation may be prohibitive. Additionally, individuals in rural areas are likely to have less access to certain technologies, such as the Internet, and may not be able to use them proficiently (Hale, Cotten, Drentea, & Goldner, 2010).

Finally, interpersonal communication theory can be used to understand health, beginning with patient-provider communication. Kreps (1993) points out that poor health outcomes can be linked to shortcomings in interpersonal communication between a patient and her/his doctor. Some of these shortcomings include patient noncompliance due to failure to establish effective communication relationships, misinformation due to inaccurate interpersonal interpretations, and insensitivity due to lack of interpersonal respect (Kreps, 1993). As mentioned before, individuals in the Appalachian region have an inherent mistrust of traditional health information providers (such as doctors and nurses), which means that establishing trusting interpersonal relationships are that much more important in the Appalachian area. McAlearney, et al. (2012) conducted a study with Appalachian women in which they examined cervical cancer screening behavior. Among women who had good interpersonal relationships with their providers and felt that their providers were listening to them, their providers were able to positively impact their screening behavior. Camacho, Hwang, Kern, and Anderson (2015) found that on-going primary care encounters (PCEs) are associated with lower rates of late-stage cancer

diagnoses, which is an argument for finding ways to build relationships among Appalachian patients and their doctors. Further, Vyas, et al. (2012) found that Appalachian women who had received care from an OB/GYN within the previous year were more likely to receive a mammogram. In addition to improving relationships between Appalachian women and their primary care physicians, breast cancer mortality rates may also be lowered by increasing access to gynecological care.

In addition to patient-provider interpersonal relationships, it is also important to understand how familial and social interpersonal relationships impact health. Bylund and Duck (2004) point out that family communication has an impact on every aspect of health, from everyday health issues, such as diet, to choices about health behaviors, such as smoking and drug use. Duggan (2006) highlights the idea that social support from family and friends has the potential to enhance well being. With regard to breast cancer, Jones, Denham, and Springston (2006) found that, especially among younger women, discussing breast cancer with a friend or relative increased the likelihood that a woman would be screened for breast cancer as well as conduct regular breast self-exams. In a study that examined Appalachian women's knowledge of breast and cervical cancer screening, Schoenberg, et al. (2013) discussed how families can act as both a motivator and deterrent for women considering cancer screenings. For example, a women who has no family history of breast cancer might be reassured by the lack of family history and decide not to engage in screening behavior. This study also found that mothers set the example of health in families. If girls grow up in households in which their mothers receive cancer screenings, the girls are likely to engage in similar behavior when they

become adults. On the other hand, because information from family and friends is mostly anecdotal, this source of information is likely to perpetuate cancer narratives that feature negative outcomes, which can lead to a higher perceived risk for cancer (Vanderpool & Huang, 2010).

Summary

The categories of literature covered here are meant as a starting point for the researcher to become sensitized to the topic as well as develop initial inquiries into this subject (Corbin & Strauss, 2008). Culture, social determinants, the use of nontraditional sources/channels for health information have been found in relationship to the Appalachian region; however, few studies have explored these components as they relate to breast health communication in the Appalachian region. Additionally, health communication theories explain effective ways to share health information, but few studies have asked Appalachian women about their preferences related to information format and presentation. These topics will be revisited and expanded upon in the analysis and discussion sections of this study, along with other pertinent concepts that emerge from the data.

Chapter 3

METHODOLOGY

The Qualitative Paradigm

Qualitative research most often hails from the constructivist paradigm. Guba (1990) describes paradigms as sets of metatheoretical assumptions that guide the research process. Paradigms address questions such as: What is the nature of reality (ontology)? What is the relationship between the knower and the known (epistemology)? How does a researcher approach finding knowledge (methodology)?

The constructivist paradigm employs a realist ontology, which means that realities are viewed as multiple, socially constructed, and context bound (Guba, 1990). The current study is conducted with respect to this ontological perspective as the researcher is not looking for one dominant perception of breast health, but rather seeking a comprehensive range of perceptions for breast health within a Southern Appalachian community.

Epistemologically, the constructivist paradigm, takes a subjectivist point of view. This point of view posits that knowledge emerges from the interaction between the inquirer (researcher) and the inquired into (phenomenon/participants). This epistemology also informs the methodology in qualitative research. Methodologically, constructivists believe that the "real world" should be reconstructed "at the only point at which it exists in the minds of the constructors" (Guba, 1990, p. 27). This study strives to fulfill both the epistemological and methodological demands of qualitative research through the use of an appropriate research method.

First, the use of in-depth interviews (described below) will allow the researcher to interact with the phenomenon being researched. Next, this study does not seek to test a theory or pre-conceived set of assumptions, but rather let meaning develop through an emergent research design (Corbin & Strauss, 2008; Glaser & Strauss, 1967). Unlike most quantitative research methods, which require most research design decisions to be made *a priori*, an emergent design allows adjustments to be made throughout the research process to ensure the researcher is gaining accurate insight into the phenomenon of interest. For example, qualitative research uses theoretical (described below) rather than random or statistical sampling. Additionally, interview guides are fluid rather than highly structured so the researcher may ask follow-up or probe questions based on individual participant responses (McCracken, 1988). Questions may also be added to or dropped from the interview guide at any time, as they are deemed more or less useful.

The In-Depth Interview

Participants in the current study took part in one-on-one, in-depth, recorded interviews with the researcher. Unlike more quantitative research methods that require researchers to be as objective and far-removed from their research participants as possible, the qualitative paradigm advances the assumption that the only way to gain insight into phenomena from the participants' perspectives is to ask them directly about their experiences with, thoughts about, etc. that phenomenon (McCracken, 1988). Interviewing and observing participants in as natural a setting as possible also adds to the researcher's understanding. For this study, the researcher traveled to Claiborne County, Tennessee to interview participants in a familiar setting, which enriched the interview

findings. Women were interviewed in the conference room of the local hospital, and information providers were interviewed at their place of business or hospital, whichever location was most convenient. As an incentive for participation, each participant received a gift bag containing health information brochures, lotion, hand sanitizer, key chains, and small photo albums. Items for gift bags were donated from a local breast health foundation and a local drug store. Additionally, all participants were offered bottled water and pastries during their interviews. Because the Health Insurance Portability and Accountability Act of 1996 (HIPAA) prohibits asking individuals about their health history, participants self-screened as having never had breast cancer.

Recording is important to the interview process because the value of the data being collected lies in the context provided by the participant. Additionally, recording the interview allows the researcher to produce a transcript from which direct quotations can be accurately taken and used in the data presentation. All interviews were conducted in accordance with IRB protocols.

Pilot Study

An interview pilot study was conducted with participants from Claiborne County, Tennessee. One person from each participant group (women and health information providers) was interviewed. The pilot study was used to affirm the usefulness of interviews as a method for data collection as well as suggested additional questions/topics to address in the interviews.

Participants

Sample

Claiborne County, is located in East Tennessee, along the Kentucky border. This county was chosen for this study because it is a "representative, typical" county in the Southern Appalachian region (Yin, 2003, p. 41). This county was also chosen due to its high breast cancer mortality rate and because it has a particular cultural identity. Studying people in this county, who share cultural characteristics similar to those in other Appalachian counties, may help researchers understand perceptions of breast health in areas with similar mortality rates and similar perceived barriers to breast health. Such understanding of how cultural identity affects attitudes toward healthcare could be applicable to other sub-cultures. Claiborne County (population: 31, 592) is very rural and predominately white (96.7%) (US Census Bureau, 2014). Approximately 22.9% of the population lives in poverty (US Census Bureau, 2014), and unemployment was approximately 6.7% in 2015 (Claiborne County Chamber of Commerce, 2015). According to 2014 Census estimates, approximately 75% of individuals aged 25 or older hold a high school diploma, with approximately 12.3% of the same holding a bachelors degree or higher (US Census Bureau, 2014).

In terms of cancer, Claiborne County is in the top 15 counties in Tennessee for incidence rate for all cancers (515/100,00) (Tennessee Department of Health, 2012) and ranks 78 out of 95 counties for cancer mortality (292.2/100,000) (TACIR, 2015). Regarding breast cancer specifically, Claiborne County has a breast cancer incidence rate (116/100,00) that is higher than the Tennessee state average (115.6/100,00), but slightly

below the US incidence average (117.7/100,000) (Tennessee Department of Health, 2009). Overall breast cancer mortality in Claiborne County (25.3/100,000) is slightly lower than overall breast cancer mortality for the state of Tennessee (26.1/100,000), but slightly higher than overall breast cancer mortality for the US (24.4/100,000). What makes Claiborne County and interesting case in terms of breast cancer is, despite its low overall breast cancer mortality rate, the Caucasian mortality rate (41.8/100,000) is markedly higher than the same statistic for both Tennessee (24.5/100,000) and the US (23.8/100,000) (Tennessee Department of Health, 2009)

Interviews

In-depth interviews were conducted with two groups for this study: Women age 18-64 who have never had breast cancer and individuals identified as breast health information providers, such as doctors and nurses. Participants were 30 women age 22-61 and four health information providers (one gynecologist, one radiologist, one nurse, and one medical student). A total of 15 health information providers were asked to participate in interviews; however, only four accepted. While the number of interviews was small, the health information providers represented a range of service areas in which breast health information is provided. Interviews with health information providers were used to contextualize the interview with women and confirm that the attitudes and experiences explicated by the participants in the study were typical and to confirm the broad themes found in the data. Additionally, the researcher found consistencies among their interviews. The researcher identified participants and gained entry into this area using contacts in Claiborne County who are affiliated with a not-for-profit breast cancer

foundation as well as contacts at Claiborne County Hospital. Sampling in qualitative research also adheres to the idea of emergent design. Theoretical sampling allows the researcher to sample where the data takes her or him (Corbin & Strauss, 2008), which means that the researcher must follow up on any analytic leads uncovered by data analysis. As Corbin and Strauss (2008) explain,

> The procedures for theoretical sampling are simple: the researcher follows the analytic trail. Perhaps the easiest way to convey what I am trying to say is to jump ahead to the study of Vietnam War combatants that begins in the next chapter. During the first interview, the participant (a nurse) described his Vietnam War experience "as not too bad." This led the researcher to ask, "How come?" What made his experience not so bad, when all I had heard from Vietnam and other war veterans in the past was how terrible war is? Could that difference be attributed to the fact that this participant was not a "combatant"? From this insight, the researcher set out to interview "combatants" to see if this did indeed make a difference in the "war experience" (pp. 146-7).

In addition to theoretical sampling, the researcher will also use snowball sampling, which assumes that members of a given population know each other (Singleton & Straits, 2005). Initial participants identified through the not-for-profit breast cancer foundation and Claiborne County Hospital were asked to pass along study information to other women in their age group who have never had breast cancer. Additionally, participants were advertised for in the hospital, local library, and local newspaper, the *Claiborne County Progress.*

Data collection for interviews concluded when the researcher reached "redundancy" or "theoretical saturation" (Corbin & Strauss, 2008, p. 263). Theoretical saturation means that not only are there no new themes emerging, but also that all viable leads yielded by the emergent design have been followed up on and incorporated into the data analysis (Nicholls, 2009).

Interview Protocol

All interviews, except one, took place at Claiborne County Hospital in New Tazewell, TN. One health provider interview was conducted at the physician's office. Located in the middle of town and close to businesses where women in the community shop and work, the hospital was a familiar and convenient location for participants.

Each interview began with the participant signing and IRB-approved consent form (see Appendices C and D), which outlined the purpose of the study as well as ensured participant confidentiality. The researcher explained to each participant that she was not looking for particular answers to her questions, that she just wanted the participant's opinions. A discussion guide was used to during the interview (see Appendices E and F), beginning with general inquiries about the participant, such as her age, work and home life, and moved into more specific questions regarding her thoughts about breast health and what influenced her ideas about breast health. Participants were allowed to speak freely about their ideas and given the option to refuse to answer any question they chose. At the end of each interview, each participant was given a gift bag as compensation for her time.

Data Analysis

Data were analyzed using the constant comparative method (Corbin & Strauss, 2008). Because qualitative inquiry uses emergent design, data collection and analysis occur simultaneously, not consecutively. So that the reality of the participant may be reconstructed as closely as possible, it is important for the researcher to collect data, then consider it in terms of both the literature and other data that has already been collected.

Immediately situating data this way allows the researcher to ask better, more introspective questions of the next participant. Since the researcher used a grounded theory approach, both the interview and documentation analysis will us the open, axial, selective coding scheme described by Corbin & Strauss (2008).

Each interview was transcribed and analyzed by the researcher using open coding. Open coding involves (1) reading each manuscript from beginning to end, (2) breaking data into manageable chunks, (3) examining each chunk in detail, (4) giving each chunk of data a carefully considered conceptual label, and (5) comparing subsequent chunks of data to each conceptual label (Corbin & Strauss, 2008). Conceptual labels assigned during open coding are not final, nor are they meant to be. A researcher will revisit and revise conceptual labels and categories as the analysis process progresses.

Next, axial coding was used to collapse the data into more refined categories. At this stage, the researcher begins to differentiate between lower- and higher-level concepts as well as link and elaborate on conceptual categories (Corbin & Strauss, 2008). Axial coding is described as "putting together a series of interlinking blocks to build a pyramid. The pyramid represents the entire structure, but blocks and how they are arranged are the components that make it what it is" (Corbin & Strauss, 2008, p. 199).

Finally, selective coding occurred to produce a grounded theory model (Corbin & Strauss, 2008). Selective coding is the last and most abstract step in the analysis process. Selective coding involves the integration of all categories to produce a "plausible explanatory framework" about the phenomenon being studied (Corbin & Strauss, 2008, p. 264). Once the initial theoretical framework has been identified, the researcher should

check for gaps in the theoretical logic and use his or her collected data to fill in those gaps within each category (Corbin & Strauss, 2008). Once the researcher has concluded her/his analysis, s/he may use a number of techniques to verify the validity of the chosen theoretical scheme (detailed below).

Quality and Trustworthiness of Research

Quantitative research uses statistical validity, reliability and significance testing to verify research results. Because qualitative research does not submit to this type of data analysis, other criteria for assessing quality and trustworthiness of research are needed. To "verify" research findings, qualitative researchers should consider the rigor of the method employed as well as the qualifications, experience and perspective of the researcher (Patton, 2001).

Employing theoretical sampling and collecting data until theoretical saturation has been reached helps ensure the rigor of the research method in qualitative inquiry. Trustworthiness in qualitative data can be achieved by using one or more types of triangulation (Corbin & Strauss, 2008; Glaser & Strauss, 1967; Patton, 2001). Methods triangulation refers to corroborating findings by using multiple research methods. This can include using more quantitative methods (such as a survey), but the goal of the research is still to present the phenomenon from the participants' perspectives (Patton, 2001). Source triangulation involves collecting data from a variety of sources, which can mean collecting data from individuals who have different relationships to the phenomena or re-visiting previously collected data (Patton, 2001). In the context of this study, choosing to interview two different groups as well as using documentation analysis

represents source triangulation. Finally, a researcher may use theory triangulation, which involves analyzing data in light of multiple theoretical frameworks (Patton, 2001).

The most important aspect of qualitative research is accuracy, or the idea that research results reflect the perspectives of the participants. There are two specific ways to ensure accuracy. First, the researcher can summarize his/her research findings and conduct a member check. This is where a member of the sample population (not necessarily one who has participated in the research) reads the summary and determines whether the researcher's interpretation of the findings reflects that population's lived experience (Patton, 2001). Another way to ensure accuracy is to conduct a peer audit. Especially when building grounded theory, it is useful to have a fresh set of eyes determine whether the researcher has made logical, plausible theoretical assumptions based on the data s/he has collected (Corbin & Strauss, 2008). For this study, the researcher plans to use member checks with each of the two interview groups as well as peer audits.

To further enhance the quality and trustworthiness of qualitative research, Patton (2001) suggest that the researcher should fully understand the paradigmatic assumptions that his/her research inquiry adheres to as well as have some practice using qualitative methods. Patton (2001) goes on to explain that researcher must understand the experience and perspective s/he brings to the research and be aware of how it may influence the research process. Because the research for this study is a native of the Southern Appalachian region, she used bracketing as a way to become more aware of her own assumptions about the phenomenon. Bracketing involves the researcher keeping a journal

or log of her/his thoughts and feelings as data collection and analysis unfold to keep them separated from the data itself.

Summary

The present study used qualitative interviews to explore how women and health information providers define breast health in one Southern Appalachian community. Thirty-four interviews were conducted; however, three interviews were removed from the data set at the participants' request. The transcripts of 31 interviews were analyzed using Corbin and Strauss's (2008) open, axial, selective coding method, which allowed themes to emerge from participants' own words and thoughts on the subject of breast health. Additionally, analysis of additional mass media and printed documentation was used to further illuminate the concept of breast health in this community. Quality and trustworthiness within the study were maintained using pilot interviews, the redundancy criterion, triangulation, member checks, peer audits, and bracketing. The following chapter provides a description of the findings and a discussion of the themes that emerged from the data.

Chapter 4

RESULTS

The researcher applied the grounded theory method described in the previous chapter to analyze data. The remainder of this chapter details the data analysis procedure and describes the results of the study.

Data Analysis

The researcher's goal was to build theory using the grounded theory method. Of theory-building, Corbin and Strauss (2008) stated "Developing theory is a complex activity. What is meant by theory? In this case, theory denotes a set of well-developed categories (themes, concepts) that are systematically interrelated through statements of relationship to form a theoretical framework that explains some phenomenon" (p. 55). This researcher sought to understand how women in one Southern Appalachian county define and maintain breast health.

In accordance with grounded theory, data were simultaneously collected and analyzed. Corbin and Strauss (2008) point out that data analysis should begin as soon as the first interview is concluded because "the first data serve as a foundation for further data collection and analysis" (p.163). The researcher transcribed and coded each interview within a few days of data collection. This process allowed the researcher to expand the interview guide to accommodate new concepts introduced by interview participants. After each interview was transcribed, it was analyzed using the three levels of coding prescribed by Corbin and Strauss (2008): open, axial and selective. The researcher spent approximately 270 hours collecting and analyzing data.

Open Coding

Corbin and Strauss (2008) describe open coding as "breaking data apart and delineating concepts to stand for blocks of raw data" (p. 195). This process allows the researcher to identify and name concepts that will make up the final theory.

During the open coding process, the researcher printed each transcript and marked codes (concepts) using a highlighter directly on the transcript. As concepts were identified, they were added to a master list of codes (see Appendix G), and the participants who discussed each concept are noted by the term using the interview number (P1, P2, P3, etc.). As more interviews were completed, transcripts were cut and placed into piles based on similarity. Because the researcher used similar codes to mark each interview, patterns emerged when the codes were alphabetized.

After all the data were coded, 70 open codes were entered into the master list. An example of an open code is demonstrated in the interview with P27. She described reasons why breast health should be taken seriously by stating, "If you are not very diligent in breast health, you know, keeping up your mammograms or having your exams or whatever it could be a cause for your health to fail or your life to end." This idea was coded as "breast health is important."

As the master list of concepts grew, the researcher created preliminary themes and categories in a Word document. For example, P27's comment about being diligent in breast health was noted as part of a larger category of "recommended breast health maintenance practices." These preliminary categories and themes transitioned the research into the second stage of coding, axial coding.

Axial Coding

After open coding is complete, the researcher moves on to axial coding, which Corbin and Strauss (2008) describe as "crosscutting or relating concepts to each other" (p.195). This process allows the researcher to identify similarities and differences among open codes and integrate them into theory. The researcher completed axial coding by sorting open codes into categories into a table. Categories represented attitudes, beliefs, behaviors, etc. As the codes were sorted, primary and secondary categories emerged, which allowed the researcher to outline the data. For example, "faithful people experience better health outcomes" and "faith helps health generally" were sorted into a subcategory of faith influencing health positively. Later, the subcategories were combined to create larger, preliminary categories. For example, "relationships with God impact health positively" and "family relationships impact health positively" were combined to create the broader category of "the belief that personal relationships are important to breast health."

Following axial coding, four categories emerged: (1) the belief that breast health maintenance through recommended practice is important, (2) the belief that personal relationships are important to breast health, (3) the belief that culture detracts from good breast health, and (4) the belief that circumstance detracts from good breast health. Each of these categories helped the researcher answer the question "what's going on here?" (Corbin & Strauss, 1998, p. 113).

The subcategories of each axial category help the researcher more clearly relate concepts during axial coding. For example, the researcher can ask

"who…when…why…how, with what consequences" do the concepts occur (Corbin & Strauss, 2008, p. 199)? By "thinking through comparative situations," the researcher knew what to look for in future interviews (Corbin & Strauss, 2008, p. 199). The integration of subcategories with the major axial codes (see Appendix H for full outline) allowed the researcher to more fully understand the relationship among axial codes and move on to the final stage of analysis, selective coding.

Selective Coding

As Corbin and Strauss (2008) note, selective coding begins by deciding on a central theme. The researcher should choose the theme "that appears to have the greatest explanatory relevance and highest potential for linking all of the other categories together" (Corbin & Strauss, 2008, p. 104). The open and axial codes must be further developed with detail in order to yield theory—concepts alone do not lead to theory. Instead, the process uses a framework of carefully defined categories that share some relationship and are also related to an overarching theoretical scheme (Corbin & Strauss, 2008).

The first step the researcher took was identifying a core concept. The researcher followed the guidance of Corbin and Strauss (2008) by checking for gaps in logic. As a result, the core category went through several revisions. For example, the researcher first noted that "breast health knowledge is affected," but this category failed to take into account how perceptions are affected. "Culture affects breast health knowledge" was also revised because, after reviewing the data, the researcher concluded that other factors also affect breast health knowledge and perception. After several revisions, the researcher

finally settled on a core phenomenon of "Appalachian cultural identity moderates perceptions about breast health." The researcher decided on this category because it had the best explanatory value of all the codes and concepts identified, as well as linked all the data categories together. This core category explains what the research is all about. Women in this study struggled to carry out recommended breast health practices due to the impact of region-specific traditions.

The four main categories were unified around this core phenomenon and helped further explain it. These four categories were: (1) the belief that breast health maintenance through recommended practice is important, (2) the belief that personal relationships impact breast health positively, (3) the belief that culture impacts breast health negatively, and (4) the belief that circumstance impacts breast health negatively. The next section presents the full results of the study.

Findings

After 32 in-depth interviews, the research found recurring themes in the data. The core phenomenon was Appalachian Cultural Identity Moderates Perceptions About Breast Health. In other words, women felt that some cultural components affected their breast health positively, while others affected it negatively. Using a grounded theory approach, four thematic constructs emerged from the data, which described how cultural identity moderates perceptions about breast health. The following thematic constructs describe how southern Appalachian women define and maintain breast health: (1) the belief that breast health maintenance through recommended practices is important, (2) the belief that personal relationships impact breast health positively, (3) the belief that culture

impacts breast health negatively, and (4) the belief that circumstance impacts breast health negatively. The remainder of the chapter is devoted to presenting the data used to build these themes.

The Belief that Breast Health Maintenance Through Recommended Practices is Important (Selective Code)

Across age groups, participants demonstrated an understanding of behaviors that physicians generally recommend to women as ways to maintain good breast health. Participants in this study defined good breast health as the absence of breast cancer (P21, P24, P27, P28) and the absence of physical abnormalities in the breast. This definition mirrors a very basic definition of health, which says that health is the absence of disease.

P31: Good breast health means no lumps, no cysts.

P28: No lumps, no discharge.

Recommended Breast Health Maintenance Practices (Axial Code)

As mentioned before, participants in this study identified behaviors that are currently recommended by physicians to maintain good breast health. These practices include self-exams, clinical exams, and mammograms. The literature suggests that patients from Appalachia often have difficulty retaining health information given to them. In this case, participants had no difficulty recalling these recommended practices.

P11: I think we should do the self breast exams…when you get to the age where you should have mammograms, I think you should.

P12: Routine exams, does a mammogram, and stays in touch with the doctor.

Because participants were able to recall and discuss behaviors that a physician would recommend to them, it appears that no knowledge gap about breast health exists in this group of participants.

The literature highlights how lifestyle factors, such as diet and tobacco use, can lead to poor health and contribute (on some level) to the development of chronic diseases, such as cancer. Participants, in their discussion of how to maintain good breast health, largely ignored lifestyle factors, such as diet and exercise. In fact, only three participants mentioned lifestyle factors initially, but revisited the topic later when discussing culture.

> *P19: I found out during pregnancy and stuff that diet, too much caffeine intake can affect your breasts as well as poor diet sometimes can affect it.*
>
> *P6: I think [women] have to take responsibility for [themselves]. She has to decide she is going to eat right, even if it costs a little more. I think the exercise thing as you get older is really difficult, but I think the advantages and the way you feel is so much better.*
>
> *P32: I smoke so I'm probably at a higher risk for it (breast cancer).*

In addition to understanding the recommended practices, participants also viewed them as important and understood that failing to follow these practices could lead to serious consequences.

> *P27: If you are not very diligent in breast health, you know, keeping up your mammograms or having your exams or whatever it could be a cause for your health to fail or your life to end.*

P32: If you ignore it (breast health), you're going to end up like my aunt did, dead.

Despite their knowledge of recommended breast health practices and the consequences of ignoring them, most participants admitted that they did not follow through with these behaviors on a regular basis.

P22: I'm one of those people that procrastinates, and I just don't do it.

P28: I try to take care of my body as much as possible. I do checks from time to time. I probably don't do it as much as I should, like every month or what-have-you, but I do check from time to time.

While the participants' lack of regular adherence to recommended breast health practices were attributed, on the surface, to procrastination and laziness, they spent a large part of the interviews discussing barriers to maintaining good breast health, which is further discussed later in the results.

This part of the data demonstrates that participants understand how to maintain good breast health, but often do not. Since many information campaigns focus on knowledge and not behavior, a change could be in order in how this region is approached with breast health information.

The Belief that Personal Relationships Impact Breast Health Positively (Selective Code)

The role of personal relationships as they pertain to health in Appalachia is well documented in the literature. While participants in this study cited doctors as the most trusted source of health information, they also admitted to learning about and maintaining breast health through personal relationships.

Relationship With God (Axial Code)

Faith is most often written about as a cultural component that affects health in Appalachia. In this study, participants discussed their belief in God in a way that mirrored the benefits they received from other types of personal relationships, such as those with family and friends. This study adds to the literature in that none of the participants considered faith a substitute for seeking medical care. P23A summarized this idea well when she said, *"My faith doesn't prevent me from going to the doctor."* On the other hand, several participants reported knowing someone who decided to forego medical treatment in the hopes that God would heal them.

> *P16: Like I said, the tumor came through her skin. It had to be packed. She suffered with it a lot. Like I said, she just kept her faith that everything would be okay. And it didn't turn out that way…Certain religions are that way. They don't believe in going to the doctor. And a lot of that's in this area. Kentucky, lower end of Virginia, the Lee County area, this area, you know.*

Participants viewed their faith the same way they viewed their relationships with family and friends: as a way to cope with negative health issues and a source of support.

> *P6: Faith doesn't mean that you won't get breast cancer, but I believe that it's a support system. If you are a person of faith and develop a disease, it's kind of like a test of how you react to it.*
>
> *P11: I think that if I ever had breast cancer, my faith would be a huge part of dealing with it.*

Participants also considered their relationship with God as an important part of the healing process and a way to improve health outcomes, just as a relationship with a medical professional would.

> *P23: People who are Christians have absolutely no problems with a healer saying 'I can pray for you.' I believe that prayer is a huge part of the healing process.*
>
> *P27: In my opinion, if you have a good faith, if you keep your mind and your body healthy spiritually, I think that probably helps you maintain your health a little bit better.*

Others believe that God heals through medical professionals, which means that visiting a doctor is not contradictory to faith, but another avenue to experience it.

> *P25: I feel like he (God) has doctors to help us. If we don't utilize that it's our fault.*
>
> *P28: I know that he gives doctors the wisdom and medicine but he truly is the healer.*

As noted in the literature, the participants in this study considered their relationships with God important to their health; however, none of them considered that relationship a replacement for seeking medical care.

Relationships With Family (Axial Code)

Participants also viewed their relationships with family as an important part of learning about and maintaining breast health. Participants considered their families a support system when it comes to coping with negative health situations, which is covered in the literature.

P12: Just family support and knowing that your family will be there. I've had a couple surgeries lately and [my sister] is wonderful. I think if you were ill and didn't have anybody then you would have to deal with the illness and depression and fear all alone.

Additionally, as the literature suggests, participants felt that their interactions with family encouraged them to maintain good breast health.

P20: My daughter has a lot to do with me going every year now. Me and her have these battles. 'Mom, you're not getting any younger, you need to go have a mammogram.' We kind of remind each other to do different things.

P23A: If you have somebody that's strong for breast health it's going to be passed down to their kids because they're going to be like, look, you need to check your breasts…

This study adds to the literature in that participants saw their maintenance of good breast health as something they do, not for themselves, but for their families.

P20: When some family member is really close to you, it makes you start thinking quit being selfish and do it for them.

P27: Just the fact that I do have a family and that I want to maintain my health, if for no other reason, but for them.

Given the link between family history of breast cancer and risk for it, participants also saw family relationships as a way to learn about their own risk for the disease.

P15: [M]y grandmothers had breast cancer, and I have a first cousin who had it in the last two or three years. So, yeah, as far as thinking about [breast health],

you know, the heredity and it begin passed on through family members made me more aware.

P23: [I]f you had a mom and sister, you know, a first degree relative that had breast cancer, you're obviously going to be much more on top of it…

The literature notes that family relationships are important in Appalachia, which participants also indicated. That participants learned from and were motivated by their family members demonstrates the trust that exists in these relationships, which the literature identifies as key to acting on knowledge.

Relationships With Breast Cancer Survivors

Participants saw breast cancer survivors as excellent sources of breast health information since survivors have experienced the entire process from detection to diagnosis to treatment. For the most part, participants considered survivors as a barometer of what is normal at any stage in the process. P8 illustrated this idea when she said, "It is very supporting (to know a survivor) because when you go through things like that you don't know what's normal. It is very helpful to have that group or that support or that person you could go to that would say, hey, look at this, be aware of that." As with family relationships, those with survivors encouraged participants to engage in recommended breast health maintenance practices, such as self-exams and mammograms.

P23A: They come and tell you their experience and sometimes you hear 'I wish I had done the self breast exams, and then I could have spotted it earlier.' It's a reminder to stay on top of that.

Participants also explained that survivors give them a sense of how serious the situation can become if good breast health isn't maintained.

> *P30: I worked in a hospital that had a cancer center next to it, and a lady came in and she had let hers go too long. You could smell the death about her because her breast was bad (the tumor had abscessed). And there was nothing they could do after that. I'm like, well, I guess I'll have to go ahead and [get a mammogram]. I mean, when you see something that horrible that could have been prevented…*

Finally, survivors can take the time to more fully explain technical aspects of detection and treatment procedures that a doctor might not take the time to or a woman might not think of asking a medical professional. P15 best described how educational it can be to know a survivor when she said, *"Well, I've learned that it (breast cancer) can be estrogen-fed, which I did not know that. I learned a lot of different things from her that I didn't realize until she was affected. To me, that's the best source for me in my information that I've gotten. She'll hand out things to everybody on the staff (at her job), so she's been just wonderful help to us all."*

The Belief that Culture Impacts Breast Health Negatively (Selective Code)

While personal relationships provided participants with information about breast health and motivation to participate in breast health maintenance behaviors, participants spent much of their interviews discussing how difficult it is to maintain good breast health given the culture in Claiborne County. Attitudes and gender roles are deeply ingrained in individuals during their upbringing, which can make them difficult to abandon, even in an effort to preserve one's health.

Women Don't Prioritize Their Health (Axial Code)

Gender roles tend to be more traditional in the south (Oberhauser, 1995), which means that men are typically the breadwinners while women manage the home and raise children. Even though most of the women who were interviewed worked or had worked outside the home, P14 captured the feelings of many participants about the county being behind the times when she said, *"[The south] is like some place that's being in the '50's. I mean, women don't really have that much say, their main concern is taking care of their children, their houses and their husbands. They become a servant, and everyone else is more important."* Participants believe that this "second-class" citizenry, as P7 put it, negatively affects women's health, including their breast health.

> *P19: We don't look out for ourselves unless there's a problem. Because, if you're raising children, the mother comes last. Taking care of yourself comes last. And when the mother gets sick, it affects everybody because she normally takes care of the kids. And the husband, who is normally the breadwinner, is having to do everything now.*

Paternalism may also play a role in why some women in the Appalachian region don't prioritize their health. While none of the women interviewed reported that they had been prevented from seeking breast health services by a man in their lives, they did acknowledged that some men in the area do have objections to their wives and girlfriends receiving breast and gynecological exams, especially from male medical professionals.

P21: Well, boyfriends and husbands think that's (a woman's breasts) their private area, and nobody should touch it unless it's them. Except, they would probably make an exception for a woman as long as it's not a man doctor.

Attitudes About Health (Axial Code)

Participants in this study reported receiving at least semi-regular breast health screenings, but still expressed a range of emotions about following up on health issues, including ignorance, fear, and skepticism. Participants attributed these negative feelings to the history of the region and attitudes that had been learned from relatives. P20's story about her father-in-law highlights this idea:

P20: Like my father-in-law, he's been sick for two weeks. Did he go to the doctor? No, don't have time, ain't got the money to go to no doctor. And he does, he just doesn't know. That's how he looks at it, though. Unless they really feel like they're dying or something, a lot of them don't go.

Some women who receive regular screenings, but avoid following up if an issue arises, hoping that the problem will just go away.

P12: My mother-in-law, she actually had breast cancer, and she was one that I think just thought if you ignore it, it will go away. She ended up dying, but it was a deal of, I think, she just sort of ignored it, and she didn't want it to be cancer. A lot of people ignores things hoping it's not that way.

Participants explained that fear not only prevents some people from following up on health issues, but may also keep them from going to the doctor in the first place or engaging in screening behaviors.

P11: I think a lot of people are afraid to go the doctor. They're afraid of what they'll find out…

P27: I don't do self-exams. I don't know if I'm afraid that if I find something that it would be…I…I don't know. Probably that maybe it would be nothing at all, but I would worry that it would be really something. I don't know, but I don't do them.

Despite the fact that access to health information has improved, even in very rural Appalachian areas, participants suggested that ignorance and uncertainty about how to address health issues still lingers.

P32: We're coming from a country background. You know, there are people who might be a little dumb, not dumb, but ignorant because they don't know.

These deeply ingrained attitudes may also account for the fact that some participants described feeling skeptical about the advice they received from medical professionals and the breast health maintenance behaviors themselves.

P20: I feel lumps in my breast, and I found a pretty good sized one. It doesn't even show on the mammogram and so that makes me kind of leery of mammograms period. Because my breasts are kind of big so they tell me it's really hard to detect because of the density so sometimes I feel that it's kind of useless or something to me. I mean, I know that sounds kind of stupid, but that's just how I feel.

Attitudes About Doctors (Axial Code)

The literature describes how individuals in the Appalachian area are reluctant to interact with medical professionals or trust the information they provide. As mentioned before, the women interviewed cited doctors as their most trusted source of breast health information, but discussed a long list of issues they have encountered in seeking breast care from medical professionals.

Given that the interviews centered on breast health, one of the main topics that arose about doctors was whether participants preferred a female or male medical professional for breast care. It should be noted that at the time of the interviews, the only practicing gynecologist in Claiborne County was male. Overwhelmingly, participants favored a female practitioner, which is understandable since breasts are a sensitive area and many women feel uncomfortable or embarrassed discussing such private matters with a man.

> *P6: I think it takes a woman, just from my experience, to understand what a woman goes through. I think they know as much, especially about women and women's problems, breast health, and that sort of thing.*
>
> *P14: You can kind of watch how people's mannerisms change and stuff when you're talking about something like [breasts] and if the doctor feels kind of uncomfortable. When I was young, in my 20's, I went in for a breast exam and the doctor actually blushed when he checked my breast, which made me feel very uncomfortable. I was like 'oh, hasn't he checked a gazillion?' I didn't go back to him for him to check my breasts anymore because it made me uncomfortable.*

Two participants, however, felt that a woman choosing to become a gynecologist was an odd choice. P29 summarized this idea when she said, *"I think any woman who would be interested in that kind of work (gynecology) that something is wrong with her."* This perception could be attributed to the deeply held attitudes about gender roles.

The participants also agreed that seeing a gynecologist for breast health was better than seeing a general practitioner since gynecologists specialize in women's health issues.

> *P15: That's their specialty area (gynecology). Just like what I do for a living. I ` have my education for that. So I want a doctor who is educated in the latest and best knowledge in that area.*

Participants felt that general practitioners were not up to date on the latest standards of care for breast health and not fully trained in women's health.

> *P9: I like that they're (gynecologists) an expert on what they're doing. A regular family doctor would just do a pap smear in his office. I'm not quite trusting of that situation because they're not necessarily trained in complete women's health.*
>
> *P20: I think women really need to see an OB/GYN for paps because they have more knowledge of it, because that's what they've been trained for. The mammogram, too. That's just the way I feel.*

The women in this study also pointed out that seeing their general physician for breast health might be uncomfortable for both them and the doctor.

> *P21: I have a woman gynecologist. My mom has a family doctor, and I don't think she'd want him examining her like that.*

P23A: Going to see a family doctor (for a breast exam) might make one or both of them (the doctor or the patient) uncomfortable.

Participants were more divided on whether breast health was better attended to by a local physician or one in a more metropolitan area (in this case, Knoxville). That personal relationships affect health in the Appalachian region might explain why some women prefer a local doctor; they might feel a more personal connection with someone local. Other factors, such as better technology, might encourage women to seek medical care further afield. P22 summarized the feelings of women who preferred local care when she said, *"They think they know more down there (in Knoxville). And they don't. Well, I mean, about some things I'm sure they do. A lot of the doctors, our doctors trained for them or they trained our doctors and lab people. I don't know why they think that, I guess 'cause it's bigger so we just say a lot of people's got Knoxville-itis. I was just in Knoxville last week, myself, and I'd much rather be here because the people know you, so you're going to get better care than at Mercy or Fort Sanders where they don't even know you. They're like, 'I don't care.*'" P19 made the case for seeking care in a more metropolitan area:

P19: Unless you go to Knoxville and you're given a really good doctor, you don't know the newer options or the newer procedures or the newer treatment. You know, you're just not subjected to that. You just go by the plan of treatment your doctor wants you to have. I know that the machine for the mammograms is not the most up to date her.

Finally, some participants expressed reluctance at visiting any doctor at all.

P14: Well, I don't really go (to the doctor) and discuss breast health with my doctor.

P22: I very rarely go (to the doctor) if I don't have to go, you know? I'm one of those 'if it's not broke, don't fix it' types.

The most common reason the participants in this study cited for not visiting doctors and/or discussing breast health with them was that in past experiences the women felt they were not listened to. As P6 pointed out, *"I've had doctors in the past that just would not listen. So sometimes I think a woman's intuition is better. Doctors don't like to hear that. I think a doctor who will listen is a good way to go and, if they don't, then you just move on."* In addition to not being listened to, participants also felt that they were being rushed through their appointment, which made them reluctant to raise issues with the physician. As P14 said, *"Everybody's in a hurry, though, and, you know, there's somebody else waiting behind you so I don't take time to really talk to them (the doctors), either."*

Modesty (Axial Code)

In discussing how they interacted with physicians, participants raised the issue of modesty. Many of them felt that breast health was not an issue they would feel comfortable discussing, not just with a doctor, but also with anyone, including close family or friends. As P20 noted, *"I just can't imagine calling up a friend and saying, 'hey, you know, we have to check our breasts today.' I mean, I'm a lot more open than I ever was in my life since I've lived here, but to me, I was always taught you keep things like that private."* If some women are reluctant to even discuss breast health with a

physician, that same hesitation may keep others from seeking breast health services at all. Participants discussed how they are generally private about health issues, but that the topic of breasts is particularly taboo due to its sexual connotation. As P14 stated, *"There's a huge sexual thing about breasts. I don't know if it's that and the fact that [people] are raised so genteel that they won't talk about it or what."* Some participants discussed how this attitude about breasts even permeates attitudes toward breastfeeding. P14 continued, *"They think of breasts as something, not to feed a child with, but more of a sexual thing, and that's off limits to a lot of people. I think that's why people don't discuss breast health or anything because you say breast and automatically think of something besides feeding a child. So I think that's maybe why it's taboo."*

Attitudes About Outsiders (Axial Code)

Another cultural component that participants in this study discussed was in-group/out-group dynamics. Participants not native to Claiborne County considered in-group status a birthright. No matter how long these women had lived in the county, they were still considered outsiders by individuals born in the county. These women also perceived that natives were more likely to share information with and trust information from other in-group sources. P3 summarized the feelings of many participants who were not born in Claiborne County when she said, *"I've lived here 15 years, but I'm still an outsider. I know the girls at my work, but my social circle is not really extensive. I mean, I know my customers, and I know when they come in, if they share with me…and there are some that have. But it's still really closed."*

Given that many health resources in Appalachian communities come from outside the area, it is easy to understand how this attitude could affect health negatively. For example, mobile mammography units from UT Medical Center regularly offer breast screening services in Claiborne County. Individuals who do not trust outsiders are less likely to utilize these services, and the ones who do use them might be less likely to follow up in the event that an abnormality is found. Additionally, medical students from Knoxville and Lincoln Memorial University often come to more rural areas to train, which might be feeding the cycle of mistrusting physicians in the area. Participants pointed out that medical professionals who come into the area from the outside often stereotype residents and disrespect the Appalachian culture.

P6: When people come from Knoxville, they are disrespectful of the culture here. And it is easy to talk down to people.

In other words, people from outside the area tend to treat county residents like they do not know anything. As P6 continued, *"So when you come to Tennessee, take your time and realize that we've done some things right. Don't go fast. Be open and receptive to understanding the way people think, take time to do that. Get to know the people, get involved. Don't just charge in…so people can trust you."* Because individuals in the area appreciate personal relationships and build trust over time, participants noted that outsiders should take the time to get to know people, and let people have time to know them.

The Belief that Circumstance Impacts Breast Health Negatively (Selective Code)

While long-held cultural traditions and attitudes can make it difficult to maintain overall and breast health, participants in this study also discussed more individual circumstances that can negatively affect health further. While any one of these issues might make it harder to be healthy, the literature documents how the Appalachian region often experiences not one of these issues, but all of them. This complex mix of poverty, poor environmental conditions, limited education and access to information, and poor lifestyle choices often creates a seemingly unbreakable cycle of poor health. Combined with the previously outlined cultural factors, these circumstances clearly illustrate how health situations can quickly become insurmountable.

Financial Factors (Axial Code)

Many participants raised the issue of cost and the local economy as deterrents to good health in general, including breast health. Despite measures, such as the Affordable Care Act, 16% of Claiborne County residents are still uninsured and the trend is that the number of uninsured residents is increasing, rather than decreasing (County Health Rankings, 2015). The area does not attract high-paying jobs, which means that individuals who work in the county might be both uninsured and receiving low wages. Some people in the area feel that the most affordable health policy is not getting sick. Individuals with no insurance often turn to emergency room visits to address health concerns, which can cost more than $1000 each time. Even individuals who are insured might have trouble meeting the cost of co-pays or prescriptions. Paying for those expenses might mean sacrificing other, equally essential items. As P14 stated, "*Okay,*

look, even with our insurance here the office visit is $35. So if you didn't have insurance, you're a farmer, and you have no insurance, are you going to go in for a well check-up? No. You can't afford the office visit and pretty soon you can't afford the gas if you do have a vehicle to get to the office."

> *P32: We have insurance, and my husband draws a decent pension, but by the time the bills are taken care of and we get food in the house, if there's medication…For myself, not my husband, I have one that is $71, it's for an inhaler. I will not get it. I don't have enough money to cover it so I don't get it.*

Individuals who may have had health benefits through their jobs previously are also facing financial hardship due to the changing economy in the Appalachian region. Factory work is often the economic centerpiece in rural counties, and many of those jobs are disappearing. As P19 stated, *"There's factories, that's you main income plus coal mining, and a lot of the factories, because of the economy, have shut down or let people go. So now people that used to take good care of themselves, do their regular visits, and keep up with stuff are not doing that."*

Difficulty of Travel

Many participants mentioned travel alongside cost as a deterrent to both general medical care and breast care, especially for women who lived outside town, in the county. The cost of traveling for care is prohibitive for a few reasons. First, paying for gas might be difficult. Also, if tests or treatment will take more than one day, individuals must consider how they might pay for hotel accommodations, meals, and other incidental experiences. As noted earlier in this chapter, patients from Appalachia are already weary

of out-group members, which can add pressure to a situation in which they have to travel to see a doctor. P14 summarized concerns about travel perfectly when she said, *"Sometimes when you live back in the mountains you don't have the transportation, a way to get out. Sometimes you have nobody to depend on so getting there (to town) is half the problem. Some people are desperate for help, but they're incapacitated by their finances, vehicle, or just plain fear to go out and get help or drive that far. A lot of people don't have vehicles and the older ones, over a certain age, maybe they've never drove or maybe their husbands drove and he's gone. So it's a bad situation and hard to get to everybody. The person who can think of how to do that, then they're going to save lives, they're going to change lives."*

Environment (Axial Code)

Given that mainly factory work and coal mining sustain the local economy in Claiborne County, participants discussed how they felt industrial pollutants in the air and water might be creating an unsafe heath conditions for residents, including putting them at risk for cancer. As P19 stated, *"I think, in general, that there's more cancer for this region, but my theory is that since coal is such a vast, the main production here, and just knowing where, like, my mom grew up that a lot people didn't have purified water and stuff."* The main environmental concern participants in this study had was living in such close proximity to Oak Ridge National Laboratory (ORNL). Located approximately 60 miles southwest of Claiborne County, ORNL is a nuclear research facility that conducts highly sensitive and often classified projects for the Department of Defense. Participants in this study felt that activities at ORNL were posing health risks for them, especially

since details of the research conducted there are not public. Even participants who felt the area was less polluted than a more urban area, such as Knoxville, were concerned about ORNL.

> *P4: We're close to Oak Ridge. Yeah, we're up the valley, the air stream from Oak Ridge. You never know what's going on in Oak Ridge. You never know what's being carried in the air, in the water or whatever. You never know.*
>
> *P7: Actually, I think this is a healthier environment here to live in versus Knoxville. I think there's less pollutants in the air, but there again, too, we're downwind from Oak Ridge laboratories. I think all in east Tennessee, we are in a higher rate for cancers because of the nuclear discharge and all the discharge that comes from Oak Ridge.*

If individuals believe they will get cancer from substances in the environment anyway, they might be less likely to engage in maintenance behaviors, such as self-exams and mammograms.

Education (Axial Code)

The literature suggests that individuals from Appalachia tend to be less educated than even their non-Appalachian, rural counterparts. Participants in this study felt that a lack of health education in particular might affect an individual's ability to make informed health decisions, including those about breast health. Many participants discussed how they had observed the progression of health education (or lack thereof) through their children who currently attend school in Claiborne County. As P30 stated, *"Educationally, I think there could be a better environment for health because people are*

just not as educated as we seem to be, you and I. They should be teaching [breast health] in middle school." Lack of health education, specifically breast health, might stem from the fact that breasts are considered an inappropriate topic for discussion.

Access to Information (Axial Code)

Participants were asked about where (if at all) they sought information about breast health and which sources of information they trusted most. They were also asked about their perceptions of the health information environment in Claiborne County. Participants felt that some aspects of the information environment could help or hurt the spread of breast health information within the community. Participants were divided on whether they felt there was enough information about breast health in the community. Some participants said there was enough information, but only for those who were seeking it. As P6 noted, *"If they're seeking it, they're looking for it (there's enough information), but I cannot speak for someone who will not take the time to do that."* Other participants felt that information about breast health was confined to doctors' offices and other medical facilities. P13 summarized the feeling of several participants when she said, *"Not in this community, I mean, as far as just thinking about my typical drive through town there are no billboards. I really don't hear that much on the radio. You've got a lot of our older folks in the community that really don't use the Internet so I'm going to say unless you're in the doctor's office on a sick day and just kind of see a pamphlet sitting around I really don't think there's enough information."* Since both the literature and participants in this study suggest that many women are not visiting medical

professionals at all, reaching many women in the area might require information to be placed in more public areas.

Regarding access to information, many health professionals predicted that as Internet access expanded, health information gaps, particularly in rural areas, would diminish. The Internet was supposed to be a great equalizer in terms of reaching populations that, otherwise, wouldn't have access to health information. Overwhelmingly, participants in the study reported that they were *not* accessing health information, including breast health information, on the Internet. Of the few participants who did look on the Internet for health information, some of them couldn't remember the websites they used, which raises questions about the quality of information women might be accessing. As P7 stated, *"I got online, on the Internet and started doing research on the estrogen and all the things that could happen from having a hysterectomy. There's a medical site that I keep going to, but I can't remember the name of it."*

Participants in this study felt that one of the best ways to share information in their community was through word of mouth. This finding makes sense because the literature suggests that Appalachian women are more likely to trust those with whom they have a personal relationship for information about health. As with many behaviors in the Appalachian area, sharing information by word of mouth often begins at home:

> *P2: There's six of us girls in my family, and we have what we call 'sisters night' that we talk about everything, including breasts. It's like a network. Some kind of women's networking group or some sort would be a good idea.*

Participants in the study agreed that information would be more attended to if it comes from someone they know and trust than information shared by a medical professional.

> *P14: Somebody that you know really cares makes a bigger impact than somebody that; it's their job.*
>
> *P15: If I discussed [breast health] with a family member or a friend, I would probably be more likely to pay attention and take it to heart.*

While word of mouth might be the most comfortable information-sharing situation for individuals in the Appalachian region and more trust exists in personal relationships, this method does raise some concerns about accuracy of information. As information is passed from one person to another, facts may become distorted to the point that individuals are sharing misinformation. Additionally, cancer is an incredibly personal and widely experienced phenomenon in Appalachia. Every participant in this study knew someone personally who had died from cancer. In many cases, those experiences represented worst-case scenarios. Since these experiences are likely to be shared alongside other information, they might be mistaken for factual, rather than anecdotal, information. Anecdotes that center on extreme outcomes, such as P16's experience with her sister whose tumor abscessed through her skin, might perpetuate the myth that seeking medical treatment won't change health outcomes or make listeners fearful of finding out they have a serious medical condition.

Lifestyle Factors (Axial Code)

Since individuals in the Appalachian region might be more likely to have limited education and access to information, their lifestyle choice could make it more difficult to

maintain good health, including breast health. Participants in this study discussed several lifestyle behaviors that they felt were negatively affecting health. Not surprisingly, one of the behaviors mentioned was drug use. In recent years, both the media and academic research have highlighted the drug problem in Appalachia. Individuals in this region are likely to abuse prescription pain medications obtained legally for vague health problems, such as back pain. Many areas in Appalachia, including Claiborne County, are gaining reputations for widespread use of illegal street drugs, such as methamphetamines. As P9 stated, *"There are a lot of drugs in this county. Meth labs are, like, every 20 miles. We don't talk about it, but we know they exist. We know they're doing drugs, know they're selling drugs. Ask the sheriff; he'll tell you."* The southern diet may also negatively impact health. Many traditional southern dishes are friend and/or made with ingredients high in fat, such as butter and lard. As noted in the literature, rates of obesity are high in the Appalachian region. Individuals in this area are also more likely to engage in known negative health behaviors, such as tobacco use. P21 summarized many of the lifestyle components of health in Appalachia perfectly when she said, *"We don't eat right; we don't exercise. I guess we smoke more than other parts of the country. I don't think people really get regular check-ups, either."*

Interviews with Health Care Providers

Interviews with medical professionals were conducted to give context for better understanding the perceptions found in the interviews with women. Information for this data set was comprised of four interviews with medical professionals (one gynecologist [PG], one radiology technician who performs mammograms [PRT], one medical student

[PMED], and one nurse [PN]). Interviews with these professionals were a way to check the results of this study against wider trends in the county since they have experience with hundreds of women, far beyond the 32 interviewed by the researcher. The professionals did not address every category of data discussed by the women, but that makes sense. The medical professionals have experience with women who have already taken a step that others in the county either cannot or will not: they have sought medical care. Because the women these professionals encounter are actively maintaining their breast health through recommended practices, we can assume that they, like the women interviewed for this study, believe that maintaining breast health is important. In addition to encountering women who consider the maintenance of breast health through recommended practices important, the professionals interviewed for this study also confirmed the three other theoretical constructs found by the researcher: that personal relationships are important to breast health, that culture detracts from good breast health, and that circumstance also detracts from good breast health.

Personal Relationships are Important to Breast Health (Selective Code)

The medical professionals interviewed confirmed that they had seen the influence of their patients' relationships with God, family, and survivors affect the maintenance of breast health.

Relationships With God (Axial Code)

The professionals described the idea of faith influencing breast health (in their experiences) as rare. The radiology technician described one incident with a patient who declined further medical treatment after she was diagnosed with breast cancer: *"Well, the*

one that didn't make it, when she found her lump, she had nothing further done. And more than likely, if she had've, her outcome may have been different. See, her way of thinking, her beliefs, religion, she had faith she would be healed. She really believed she would be healed. And she would be fine. She did die; she suffered a lot with it." The gynecologist interviewed used his own experience in combination with his patient interactions to conclude that a patient's faith did not factor into her perspective on or decisions about health. As he said, *"I'd say in most churches and things, both where I'm a member of and not, fatalism is not an accepted practice."* It should be noted that fatalism is not necessarily tied to one's faith; it is simply a belief you will die from some medical conditions (such as cancer) no matter what you do or do not do to improve your outcome.

Relationships With Family and Survivors (Axial Code)

The professionals only discussed the influence of family on patients as it applied to patients having family members who were survivors. This finding also makes sense because a patient probably wouldn't share information about their familial relationships unless they were related to the patient's visit with the medical professional. The professionals explained how patients' contact with cancer survivors often prompted patients to care more about their own health or encouraged them to engage in recommended health maintenance practices.

> *PN: I've heard of women getting out there and getting their breasts take care of because of a friend or co-worker or family member that suffered or just out of the blue was diagnosed.*

PRT: Some people do come because they know somebody that's just been diagnosed with breast cancer. That does scare some of them into coming. A lot of them are influenced by their friends.

Culture Detracts from Good Breast Health (Selective Code)

The professionals mainly used their observations outside of practice and private experiences to discuss the impact of culture on breast health. This finding make sense because the women encountered by professionals in practice are obviously not deterred from seeking breast care.

Women Don't Prioritize Their Health (Axial Code)

While the women seen by professionals in practice are obviously doing something to maintain breast health, some of them discussed how patients put off taking care of themselves, not thinking about how that behavior might impact their families.

PRT: They need to think about it don't just affect them. Their family, their kids. I don't think they think about that. With some diseases like that (breast cancer), it affects your whole family.

PMED: It's like, take care of everybody else, and then we'll worry about me when everybody else is good and ready to go.

Attitudes About Health (Axial Code)

The professionals reported seeing more willful ignorance in patients. Because practitioners are involved in the diagnosis of disease, they observed how patients reacted upon receiving a diagnosis. In some cases, the reactions seemed to go beyond expected denial (which is typically temporary).

PRT: They don't want to know. They think if they don't go (for treatment) then it's going to go away.

PG: The one girl, it took me over a year to convince her that she probably had breast cancer. I had to talk her into it.

The professionals also discussed the fact that preferred to just have their symptoms treated, not be educated to their causes. While the women who were interviewed in this study did not discuss this category, it does shed light on the idea that individuals in the area are not interested in maintaining health through preventive measures, but rather restoring health through treatment after they get sick. This idea is particularly important when considering breast health since cancer is fairly asymptomatic until its later stages. A late-stage cancer diagnosis also reduces the likelihood that health can be restored through treatment. Breast cancer treatments are most effective when cancer is diagnosed early. An early-stage diagnosis can only be achieved through participation in routine screening behaviors.

Attitudes About Doctors (Axial Code)

As with the women interviewed in this study, the topic of male vs. female practitioner came up in the interviews with medical professional. The gynecologist interviewed didn't have patients who preferred seeing a female practitioner, which makes sense because he is a man. The nurse, medical student, and radiology technician all described how delighted patients often are at finding out their breast care is going to be handled by a woman. The radiology technician best summarized this idea when she said,

"And I'll answer the door and they'll say, 'I'm here for my mammogram. Are you going to be the one doing it?' And I'll say yeah. 'Pshew! Man, I'm so glad it's not a man! '"

Modesty

The professionals observed that even among women who seek breast care regularly, modesty and privacy are still apparent. To discuss this category, the professionals, again, combined what they had observed in practice with private experiences. As PRT explained, *"Maybe they'd rather think about that more in private. Some of them are kind of backward about certain things. I don't know if that's the correct word to use. It seemed to be that way with my cousin (who had breast cancer). We didn't know it for a while, until it had already got really bad. I think she wanted to keep that kind of more private. I don't know why."* As mentioned before, the women these professionals are interacting with feel comfortable visiting a medical professional for breast care, which probably means that they do not feel too modest to discuss something as private as breasts with a medical professional.

Circumstance Detracts from Good Breast Health (Selective Code)

The medical professionals interviewed for this study remarked mainly on the patient circumstances they would have occasion to know about: financial factors, health education, access to information and lifestyle factors.

Financial Factors (Axial Code)

More than any other circumstances, the medical professionals were acutely aware of the difficult financial situations their patients were in, particularly the lack of insurance among some patients.

PG: There's a big difference between Claiborne County and Morristown. Mainly just socio-economic differences, some of them because they don't have insurance.

While the women interviewed for this study did not link financial circumstances to their attitudes about doctors, the medical professionals felt that many patients believed that doctors were taking advantage of them or ordering unnecessary tests/procedures as a way to make more money. PMED explained, *"I think money also here becomes and issue because a lot of people are like, you're just running up the bill doing this or this. I hear 'I don't have insurance' a lot."* The professionals also discussed how patients sometimes believe that they won't receive treatment or will be treated differently because they don't have health insurance. PMED continued, *"We had a patient recently who told me that we wouldn't treat her because she didn't have insurance. We can't do that, and, of course, we treated her."*

Education (Axial Code)

The medical professionals echoed the women's perception that health education in particular is lacking in Claiborne County. They discussed how patients needed to be educated to preventive measures, not waiting to be treated after they get sick. As PN noted, "*I would like to see more education and government and insurance acceptance of preventive instead of waiting for the bad to happen and then handling it."*

Additionally, the professionals felt that more women would engage in recommended breast health behaviors if they were better educated about them. As PRT stated, *"They [patients] don't have a clue what they're doing. I mean, they don't, they've never been instructed on how to do it (self-exams)."*

Access to Information (Axial Code)

The medical professionals interviewed for this study felt that adequate information was available to patients. Since medical professionals have a background of medical knowledge and work in information-rich environments, their perception of available information is likely biased. As PN pointed out, "I think the information is out there. Whether or not people seeks that information, I don't know. There has to be a degree to where you have to be interested and look for yourself." The gynecologist and radiology technician both acknowledged that they have a role in their professional capacities in making information available to patients. PG explained, *"If they (patients) don't know how to do self breast exams we not only give them instructions, we give them a card for instruction."* Only the medical student described a situation in which information was provided outside the clinical setting. She described a "Think Pink" health fair that she and other students organized during their first year in medical school. She acknowledged that efforts to educate the broader community could be better: *"It's kind of hard to get it all out there, so efforts are made, but there definitely could be more. I think we have the capabilities to do it now with the right resources."* Since women who receive breast health information in a clinical setting are also receiving services, it stands to reason that offering breast health information in a non-clinical setting is an avenue to providing more services to more women.

Lifestyle Factors (Axial Code)

The medical professionals acknowledged many of the poor health behaviors that were discussed by the women who were interviewed for this study. The professionals

considered drug use and smoking as widespread problems. As PN noted, *"I know there's just a lot of people on drugs. In that respect, when they're on drugs, they're not taking care of their health. And there's a high number. I also noticed a high number of folks on medications, prescription medications for their nerves so…"* Unlike the women who were interviewed, the medical professionals drew a line from lifestyle factors to the financial difficulties many patients have. As PMED described, *"They're (patients) like, 'I can't afford my medications because I've got to buy my cigarettes. Can you write me a prescription for that so my insurance will pay I so I don't have to pay it out of pocket?'"* The professionals observed that patients often prioritize poor health behaviors, such as smoking, over caring for their health. PMED continued, *"I mean, they have no problem with cigarette smoking, they have no problem spending $8-$10 a day, but if you ask them for $10 a month payment for caring for them for a long, long time, they're like, 'Where's that going to come from?'"* Based on this finding, helping individuals overcome negative health behaviors is a way to alleviate financial burdens, which might help them better maintain their health.

Based on the interviews with four medical professionals, many of the concepts addressed by the women interviewed were supported as broader trends in the community.

Summary

Using a qualitative research approach, this chapter described how women interviewed for this study define breast health. After 32 in-depth interviews, the main theme that emerged was: was Appalachian Cultural Identity Moderates Perceptions About Breast Health. Four thematic constructs helped support the main theme: (1) The

belief that breast health maintenance through recommended practices is important, (2) The belief that personal relationships impact breast health positively, (3) The belief that culture impacts breast health negatively, and (4) The belief that circumstance impacts breast health negatively. Interviews with medical professionals confirmed that these findings represent a trend in Claiborne County beyond the women interviewed for this study. The following chapter presents conclusions drawn from the research as well as recommendations for health communicators.

Chapter 5

DISCUSSION AND CONCLUSIONS

The main theme that emerged from the data was: Appalachian Cultural Identity Moderates Perceptions About Breast Health. Four thematic constructs helped support the main theme: (1) The belief that breast health maintenance through recommended practices is important, (2) The belief that personal relationships impact breast health positively, (3) The belief that culture impacts breast health negatively, and (4) The belief that circumstance impacts breast health negatively. This chapter will (1) discuss and draw conclusions from the main theme and thematic constructs that emerged from the data, (2) develop a theoretical framework based on the findings, (3) discuss the importance for health communicators, and (4) identify suggestions for future research and outline research limitations.

Overarching Theme: Appalachian Cultural Identity Moderates Perceptions About Breast Health

Despite possessing correct knowledge about recommended breast health maintenance practices, women in this study described factors that supported their breast health as well as cultural factors that detracted from it. In addition to correctly identifying maintenance practices, participants also described those practices as important, despite finding it difficult to carry out those practices.

The Belief that Breast Health Maintenance through Recommended Practices is Important

Women in this study correctly identified recommended breast health maintenance behaviors, which include breast self-exams and mammograms. Susan G. Komen for the

Cure [SGK] (2015) summarizes recommendations across age groups to help women, in concert with their health care providers, make decisions about screening behaviors. In 2009, the U.S. Preventive Services Task Force [USPSTF] raised questions about the effectiveness of breast self-exams. Currently, breast self-exams are not among USPSTF's (2016) recommended screening practices. On the other hand, the National Breast Cancer Foundation (2009) estimates that 70% of all breast cancers are discovered by women performing breast self-exams. Participants in this study identified both self-exams and mammograms as ways to detect breast cancer early. Participants also explained that if they discovered a lump through self-exam, then they would schedule appointments with their physicians where a clinical exam would be performed, followed by a mammogram if needed. This finding is at odds with Shell, et al. (2004), which found that Appalachian women possessed low and often confused or inaccurate knowledge about breast cancer generally and screening methods in particular. Royse and Dignan (2009) also conducted a study in which knowledge of cancer screening in Appalachia was examined. While they found that knowledge of cancer screening was low across the region, women were found to be more knowledgeable than men.

The Belief that Personal Relationships Impact Breast Health Positively

Women in this study felt that their personal relationships were supportive of good breast health. Participants mentioned their relationships with God, their families, and survivors.

That participants considered their relationships with God supportive of their overall health and breast health specifically is not surprising. The role of religion in most

aspects of Appalachian life is well documented in the literature. This study supports Schreibner's (2011) finding that a belief in God is psychologically comforting and a coping strategy for bad news. Participants in this study felt that a relationship with God plays a positive role in managing health crises, as Behringer and Krishnan (2011) also found; however, participants did not view their faith as prohibitive to seeking recommended medical care. Additionally, participants in this study did not discuss prayer or faith in God as substitutes for medical care. Participants did discuss how churches could play a broader role in educating individuals about cancer screening by hosting information sessions and events, which echoes Simpson and King's (1999) suggestion for religion-community partnerships.

Beyond their relationships with God, participants felt that their relationships with their families help them understand their risk for cancer, encourage them to engage in screening behavior, and provide motivation for screening in addition to providing comfort and support during a health crisis. Helton and Keller (2010) described Appalachians as personalistic, which means they "place great value on respecting interpersonal relationships" (p. 153). This description helps explain why women in this region trust their family and friends as sources of health information more than they do their physicians. That women consider their families as sources of both information and support is consistent with those of McMillan, et al. (2007), who conducted focus group research with working women in Appalachia. Participants in this study felt that their desire to care for their families served as a motivator to attend to their breast health. Schoenberg, et al. (2013) explained that some women are reassured by their lack of

family history of breast cancer and feel that they don't need screening, but none of the women in this study reported thinking that.

McMillan, et al. (2007) also found that survivors were viewed as good sources of information, a finding that was echoed by women in this study. Participants saw survivors as more knowledgeable than non-survivor family and friends because they had been through the process of diagnosis and treatment. Women in this study felt that survivors could give them a sense of what's normal in terms of having a mammogram and following up if a lump is discovered. Documet, et al. (2008) found that Appalachian women prefer first-person narratives delivered by word of mouth. Since women tend to share stories of cancer experience that feature negative outcomes (Documet, et al., 2008; Vanderpool & Huang, 2010), the challenge becomes finding a way to circulate survivor narratives that feature positive outcomes tied to preventive care.

Because participants in the current study saw their personal relationships as one of the only factors that support good breast health, communicators should use those relationships to share breast health information. While participants viewed personal relationships as supporting their efforts to maintain breast health, they discussed many more barriers to those efforts. Deterrents to good breast health fell into two broad categories: cultural factors and circumstantial factors.

The Belief that Culture Impacts Breast Health Negatively

Participants in this study identified five cultural areas that make maintaining breast health more difficult: (1) Women don't prioritize their health, (2) Attitudes about health, (3) Attitudes about doctors, (4) Modesty, and (5) Attitudes about outsiders.

One of the main barriers to good breast health described by participants is the fact that Appalachian women don't prioritize their health. Participants explained how women place their roles as wives and mothers above their own well being. Some participants described how attending to their own health was often displaced by the needs of their husbands and children. They also explained how women might benefit from health messages that frame taking care of their own health as something they could do *for* their families rather than something that takes away from their families. This finding supports previous research that posits that women are expected adopt traditional gender roles and put family first more often than men (Rezek, 2010; Schoenberg, et al., 2013). While this gender expectation is seen generally in society, it is more prevalent in the Appalachian area. Further, Denham, et al. (2004) found that women are seen as the managers of their families' health. Their study suggested targeting mothers with health education since they educate their families about health matters.

Participants in the current study also described how general attitudes about health, many of which were learned from family members, made it difficult to maintain breast health. To begin, most participants were raised in households in which you only went to the doctor if you were gravely ill. Most participants explained that they did not receive preventive care or well visits growing up, which set a tone for medical care in their adult lives. Shell and Tudiver (2004) explained that even though cancer screening services might be available and physicians might recommend those services, none of it is possible of patients are not going to the doctor. This habit of only going to the doctor when ill also provides a strong argument for moving information about screenings outside the clinical

setting. Documet, et al. (2008) discussed that Appalachian cancer patients tend to be diagnosed in a later stage of disease, which might lead to patients feeling that preventive measures don't make a difference.

Participants in this study reported having somewhat regular gynecological exams, but some of them expressed anxiety and fear about what those exams might yield, particularly a cancer diagnosis. Worry about being diagnosed with cancer supports Documet, et al.'s (2008) findings; however, women in the current study did not express concern about a diagnosis leading to missed work as did the women in theirs. Participants in the current study did discuss being skeptical of the advice given to them by physicians. In some cases, the women felt that the exams they had weren't helpful. Vanderpool and Huang (2010) discussed how the multitude of recommended screening practices were confusing to Appalachian participants, which could lead to skepticism regarding the effectiveness of any of them. Individuals may also be skeptical of physicians' advice because it doesn't reflect the outcomes experienced by family, friends, and neighbors (Vanderpool & Huang, 2010). Similarly, Denham, et al. (2004) posit that individuals in the Appalachian area use the health experiences of their close family and friends to understand health risks and outcomes. Despite the fact that women in the current study *said* they trust their physicians most for health information, their behavior suggests that they trust individuals with whom they have personal relationships with more, which raises the issue of how women in Appalachia feel about physicians.

While women in this study named physicians as their most trusted source of breast health information, they spent much of their interviews describing their ideal

physician. In many cases, these preferences were so specific that it is not hard to believe that participants found it difficult to find a doctor they liked and/or connected with.

Overwhelmingly, the women in this study preferred a female physician when it came to breast and gynecological services, a finding that is supported by previous research (McMillan, et al., 2007). Participants felt that women were much better qualified to handle women's health issues since they were female themselves. McAlearney, et al., (2012) found similar attitudes in their study about cervical cancer screening. Participants also described feeling more comfortable and less embarrassed with a female practitioner. Preference for a female practitioner is not unique to the Appalachian region. In a review of approximately 98,000 women's insurance claims, Lurie, et al. (1993) found that women were more likely to receive breast and gynecological services if the practitioner was a woman. A few women felt that women who choose to specialize in gynecology were odd, a finding mirrored in McMillan, et al. (2007), but these women did not represent that majority of participants.

Next, participants in the current study felt it was important for them to receive breast health care from a gynecologist instead of their general practitioner (GP) or family doctor. In the case of Claiborne County, the only practicing gynecologist at the time of these interviews was male, which posed a problem for some of the participants since they prefer a female practitioner. Participants felt that gynecologists were better for breast care because they specialize in women's health issues and are more up to date on gynecological care. Additionally, some participants felt that it would be uncomfortable to see their GP around town after having been examined by him/her so intimately. None of

the recommendation guidelines specify that a gynecologist is preferred for routine breast care and previous research has found that regular visits to either a general practitioner (Camacho, et al., 2015) or a gynecologist (Vyas et al., 2012) are consistent with increased screening behavior. Camacho, et al. (2015) also found that patients were less likely to receive a late-stage cancer diagnosis if they had ongoing appointments with their general practitioners. Both participants in the current study and previous research have raised issues with the quality and availability of both general and specialist care in the Appalachian region, which is discussed in the following section.

Participants in the current study were more divided on whether local was better than that available in more metropolitan areas, such as Knoxville or Morristown. Some participants felt that local care was better due to the personal relationships they have with their providers, while others feel that more technologically advanced and up to date care was available elsewhere. One problem with receiving care locally in Appalachia is a shortage of practitioners. Anderson et al. (2014) reported that 290/420 (69%) Appalachian counties have a shortage of health professionals. These shortages lead to long waits (Huttlinger, Schaller-Ayers, & Lawson, 2004) and declining perceptions of the quality of local care (McAlearney, et al., 2012). Participants in the current study described that many local general practitioners do not schedule patients by appointment, but see patients on a first-come, first-served basis, which can make a routine appointment an all-day ordeal. Shell and Tudiver (2004) explored these challenges from the provider perspective and found that general practitioners in Appalachia often do not address cancer screening with patients due to time constraints and the perception that prevention

is not a priority among patients. Further, general practitioners reported being confused by screening guidelines themselves, which lead them to ignore the subject with patients. Women in the current study reported knowing women who would not leave the area for medical care because they are worried about travel, which is discussed in a later section.

Women in the current study felt that modesty about health generally and breasts in particular cause women in the Appalachian region to ignore breast health. Some participants said it was difficult for them to discuss the subject even with their closes family and friends. Lyttle and Stadelman (2006) found that next to cost and fear, embarrassment about breasts is the main barrier to screening reported by Appalachian women. Explanations for this level of modesty include the fact that women adopt traditional gender roles, as discussed by Helton and Keller (2010), and the influence of men. While none of the participants in this study reported being kept from medical care by a man in their lives, a few reported knowing women who had that experience. This finding is consistent with Schoenberg et al. (2013), which also reported women knowing other women whose medical decision were influenced by their husbands. The fact that none of the participants in either study reported this experience first-hand might indicate that women are reluctant to report interfering behavior on the parts of their husbands. One participant in this study later contacted the researcher to ask that her interview be removed from the data set because her husband disapproved of her participation in the study. The researcher complied with her request. In an effort to overcome the taboo subject of breasts, Lyttle and Stadelman (2006) suggest that girls should be educated

about breast health in school. Beginning this conversation early may help reduce the embarrassment attached to the discussion of breast health.

Given their long history of pride and self-reliance (Vanderpool, et al., 2007), patients in the Appalachian area may resent interference from individuals outside the region. Additionally, Ludke, et al. (2006) found that Appalachian patients had anxiety about or perceived difficulty in interacting with healthcare practitioners from outside the Appalachian region. Behringer, et al., (2007) also discussed how patients in this area are suspicious of outsiders. Women in the current study did not mention anxiety about or perceive difficulty with practitioners from outside the area, but they did perceive that these practitioners were likely to treat them as ignorant and uneducated. In addition to affecting willingness to travel outside the region for medical care, this perception also affects medical services coming into the region. Documet, et al. (2008) discussed how outsiders often come into the Appalachian area as part of their medical training, which gives locals a reason to avoid local medical offices. Additionally, in this region, mobile health services (such as mobile mammography) are not uncommon. Further, because these resources are often part of a temporary program, women in Appalachia don't have the opportunity to get to know the staff and build trust with them. Ways to more effectively incorporate outside resources are discussed later in the section Recommendations for Health Communicators.

While cultural factors are long-standing barriers that encompass the Appalachian way of life, they were not the only barriers described by participants in this study. The

women interviewed also discussed circumstantial factors that serve as barriers to good breast health.

The Belief that Circumstance Impacts Breast Health Negatively

Circumstantial factors represent barriers to good breast health that are more temporary than cultural factors and may be more easily overcome. Women in the current study identified six circumstances that make it difficult to maintain good breast health: (1) financial factors, (2) difficulty of travel, (3) environment, (4) education, (5) access to information, and (6) lifestyle factors.

Not surprisingly, participants viewed cost a significant barrier to participating in recommended breast health maintenance practices. This finding is well supported by previous research (Lyttle & Stadleman, 2006; Ramirez, et al., 2015; Shell, et al., 2004). Individuals discussed high costs of services not covered by their insurance and exorbitant emergency room bills for women not covered by insurance at all. One participant discussed that even the co-payments for services covered by insurance might be too expensive for some. While initiatives such as the Affordable Care Act have sought to increase insurance coverage, rates of coverage are declining rather than increasing in Claiborne County and other parts of Appalachia (County Health Rankings, 2015). McGarvey, et al. (2010) compared health disparities between Appalachian and non-Appalachian counties. Their study found that Appalachians were receiving inadequate care despite having health insurance. This finding could relate back to the fact that Appalachians are unlikely to seek medical care except in a dire situation.

Closely related to the barrier of cost is the perceived difficulty of travel. This barrier is also well documented by previous research (Documet, et al., 2008; Huttlinger, et al., 2004; Schoenberg et al., 2013; Shell, et al., 2004). While none of the participants in the study reported an unwillingness or inability to travel outside the county for medical care, they discussed women they know who would have a problem due to finances and/or lack of reliable transportation. Ludke, et al. (2006) described reluctance among Appalachian patients to leave the area for medical care, due to anxiety dealing with outsiders. Mobile health units present a solution to this problem, but these units are likely to be staffed with outsiders, too. Given the myriad of concerns previously raised about local medical care, increasing willingness and ability among Appalachian patients to travel outside the area for care or use mobile health units are steps that are likely to save lives. Health communicators could increase participation in mobile health units by using local women to share information about the units and on site as hosts to help participants feel more at ease.

Women in this study were concerned about the effect that the environment was having on health in Claiborne County. Specifically, participants worried that radiation from Oak Ridge National Laboratories (ORNL) was increasing rates of cancer. Health information providers felt that this concern was unwarranted and caused participants to worry unnecessarily about cancer rates. While not related to environmental concerns, other studies have found that Appalachians perceive themselves to be at a higher risk for cancer than they actually are (Vanderpool & Huang, 2010). In addition to effects from ORNL, participants also discussed effects from coal mining and pollution from local

factories as being related to rates of cancer. In a study that examined how women who lived near fracking operations in Appalachia, Resick, et al. (2013) described how industrial factors are a double-edged sword for individuals in the region. On one hand, these entities provide some of the most well paying jobs in the region. On the other hand, these industries produce pollution and other environmental hazards that might endanger health. Resick, et al. (2013) concluded that the women in their study felt powerless over their health in the face of such risks. Health communicators can create information campaigns to reduce anxiety about environmental factors and empower women in the region to take charge of their health by engaging in screening behaviors.

Participants in the current study felt that an increase in both general and health education would have a positive impact on knowledge of breast health maintenance practices. Blackley, Behringer, and Zheng (2012) theorized that improving high school graduation rates in Appalachia would significantly reduce the burden of cancer mortality over time. Denham, et al. (2004) posited that respecting the family as the seat of health education was the most effective strategy in Appalachia. Since women are responsible for the health of their families Denham, et al. (2004) suggest making them the target of education campaigns in hopes that they will share the information with their families. Documet, et al. (2008) suggested sending screening information home with school children, arguing that a mother would have difficulty saying no if her child suggested she have a mammogram. Schetzina, et al. (2009) conducted a health education program focused on childhood obesity in Tennessee schools, which proved to be successful; however, it might be difficult to justify providing health education for parents through a

school-sponsored program. Other researchers feel that health education materials should be moved outside the clinical setting to better reach more people, which is discussed in the next section about access to information.

Women in the current study felt, for the most part, that adequate breast health information was available for those who seek it. Since previous research shows that Appalachians do not value preventive care, which includes cancer screening (Schoenberg, et al., 2013), women are likely not seeking information. Additionally, participants reported that information was most readily available in clinical settings (physician offices, health departments, etc.). As discussed before, Appalachians resist going to the doctor, which means this information might not be accessed regularly. One of the health information providers interviewed for this study reported that many of his regular patients turn down printed information he provides. Participants in this study and other researchers feel that the most effective way to increase access to information about breast health maintenance behaviors is to move the information outside the clinical setting. Placing information in areas that women regularly visit is more likely to be accessed. Moving breast health information into the community increases the opportunity for health communicators to engage in media advocacy. Wallack, et al. (1993) explained how health communicators can piggyback on existing programs and events with which the target population is already familiar to reduce costs and increase access to information. For example, Bencivenga, et al. (2008) examined a program designed to increase mammography screening that was administered through a food pantry. Of the women who were eligible for a mammogram, 87% of them received one as a result of the

program. This program is an example of adapting the information environment to those who need information. Other suggestions to move breast health information outside the clinical setting include using churches and shopping centers (Documet, et al., 2008) as distribution points for information. While sharing printed material is important, participants in this study reported that word of mouth is the best way to share information in Claiborne County, a wider trend that is supported by previous studies (Denham, et al., 2004; Shell, et al., 2004). The preference for sharing information orally reflects the preference to receive information from family and friends (Shell, et al., 2004; Vanderpool & Huang, 2010).

Women in the current study mentioned television programs, such as *Oprah* and *Dr. Oz* as sources of health information. Further exploring media preferences among Appalachian women could also help health communicators develop entertainment-education initiatives that are most likely to resonate with women in the Appalachian area. Wright (2009) found that plays featuring information about diabetes were effective in educating Appalachian audiences about the disease so storylines that feature information about engaging in recommended breast health practices could be equally effective.

Since few women in the current study mentioned using the Internet as a source of health information, interactive health communication tools, such as telemedicine may not be as effective as other types of interventions, despite research that suggests the use of interactive tools (Graham, 1996; Neuhauser & Kreps, 2003; Patrick, 1999; Raza, et al., 2009; West, et al., 2010). The digital infrastructure still might not be developed enough to support interactive initiatives, as pointed out by Fotheringham and Owen (2000). Health

communicators in the Appalachian region could work to better connect women in the area with the digital tools that are available and partner with programs that increase digital efficacy and literacy.

No matter which type of health communication campaign practitioners choose, they cannot overlook the importance of coupling these campaigns with strong interpersonal elements. Both information about and effectiveness of programs should be shared using word of mouth (Documet, et al., 2008), family networks (Denham, et al., 2004), and other interpersonal networks that are already in place, such as churches (Simpson & King, 1999). Messages disseminated through mass media campaigns are much more likely to be effective with Appalachian women if they are aligned with messages from family and friends (McNeill & Dorgan, 2004).

Participants in this study mentioned three lifestyle factors specifically that make it hard to maintain good health, including good breast health: (1) illicit and prescription drug abuse, (2) diet, and (3) lack of exercise.

Schoenberg, Hatcher, and Dignan (2008) studied perceived health threats among Appalachian women. Drug abuse (both prescription and illicit) topped the list of concerns. In the past two decades, the rise of methamphetamines and other unstable street drugs have become a public health problem in Appalachia, which is often referred to as the "meth capital." Women in this study also described the trend of individuals seeking controlled pain medications, such as Oxycontin, for vague health problems (back pain, for example) and then abusing he prescription themselves or selling it to others. Schoenberg, et al. (2008) identified the drug problem in Appalachia as a "problem that

spreads like a contagious disease" (p. 8) that the region is ill-equipped to handle due to the lack of drug treatment and mental health services. While use of illicit and prescription drugs has not been linked to cancer, participants in this study felt that it was a deterrent to all types of health.

Another lifestyle factor raised by women in this study is the Southern diet, which tends to be high in fat. Concern of diet was the fifth of seven health concerns identified by Schoenberg, et al. (2008) study of health concerns among Appalachian women. According to Thompson (2012) a low-fat, high fiber diet is considered "weakly proactive" against breast cancer (p. 636). One participant reported not knowing what foods were recommended to prevent breast cancer. Popular press articles over the years have linked most foods to both the prevention of and cause for breast cancer, which could be linked to some of the confusion reported by general physicians in Shell, et al.'s (2004) study. Poor diet in the long term may lead to obesity, which Cleary and Grossmann (2009) linked to higher risk for breast cancer in both pre- and postmenopausal women.

Finally, women in this study discussed lack of exercise as a deterrent to good health. Participants in Schoenberg, et al's. (2008) study ranked lack of exercise the sixth of seven health concerns in Appalachia. Leslie, et al. (2003) described exercise as "somewhat protective against breast cancer" (p. 661). While exercise alone may not prevent breast cancer, it, combined with a good diet, can help mitigate obesity.

Understanding the circumstances that Appalachian women see as barriers to good breast health can help health communicators design more effective information campaigns in the region. Additionally, understanding these barriers can give researchers

insight into populations that face similar barriers. For example, while inner city women may differ geographically and racially from Appalachian women, they face similar barriers to health, generally, and breast health, specifically, such as cost, low education levels, and poor access to information.

Theoretical Implications: Cultural Identity Moderates Health

By understanding which cultural components influence health positively and which influence health negatively, researchers can better understand and predict how health information is sought, valued, and used. Previous studies have documented the effects of some cultural factors on health, both generally and relative to particular groups. For example, Bouchard (2009) notes that social participation and inclusion are seen as promoting health, while "being denigrated and stereotyped, feeling a sense of worthlessness and despondency, and lacking direction in one's life" can have a negative effect on both mental and physical health (p. 170).

Johnson, Hardt, and Kleinman (1995) explain four ways in which culture can affect patient behavior around illness. First, what the patient considers normal and abnormal is shaped by culture. For example, women in the current study considered dying from cancer a normal outcome, as they knew many people who had died from the disease. Next, culture also influences perceptions of disease cause. Participants in the current study felt that environmental factors Claiborne County, such as proximity to Oak Ridge National Laboratory and pollution from coal mining and factories, were largely responsible for the high rates of cancer in the area. Johnson, et al. (1995) discuss that ideas about health decision-making are rooted in culture. For example, children learn how

to respond to health issues by observing how their families and neighbors respond to similar issues. Given how family is valued in the Appalachian area, health decision-making in this region might be more collective, rather than individualistic since patients are likely to seek input about health decisions from their family members. Finally, attitudes and behavior around clinical care are also rooted in culture. Women in the current study described how preventive care is not valued in Appalachia and that people in the area are only likely to visit the clinical setting when they perceive that they are ill. Some individuals in the region will not visit the clinical setting even when they are ill, but decide to rely on their faith to get them through the crisis. Because these factors are closely related, they likely work together to produce a generally positive or generally negative effect on health perceptions and behaviors.

Ali, Atkin, and Neal (2006) discuss the potential impact of culture on clinical practice. Since the understanding of wellness and illness are rooted in culture, effective communication between patient and practitioner can only occur if their cultural lenses overlap when it comes to how health is understood. If these culturally based understandings do not align or are not respected, it is not difficult to understand why the patient might develop a negative perception of clinical care.

Kreuter and McClure (2004) explain that culture not only affects perceptions about health issues themselves, but also about the communication surrounding health issues. Understanding and respecting whom a group considers a credible source of information, the types of messages to which the group is likely to respond, and the channels through which a group expects or prefers to receive health messages are all key

in increasing positive engagement with health messages. These preferences are driven by culturally derived attitudes, values and beliefs about culture. Messages that fail to take these factors into account will likely fail to reach the target audience with their information.

Instead of considering the impact of each cultural component individually, the current study suggests that components be grouped based on how they are perceived (as having a positive or negative impact) to explain the overall effect of cultural identity on health perceptions and to create more effective communication around health issues.

Research Based Strategies and Tactics

This study helps explain how Appalachian cultural identity moderates perceptions about breast health. Based on the findings from this study, the following strategies and tactics are proposed: Appalachian women are more likely to follow recommended breast health practices if the communication around these practices:

I. Is built on interpersonal communication components. For example:

    A. Includes narrative components, such as personal stories, which are easy to remember and share

    B. Adopts "word of mouth" components, such as "tell a friend" campaigns

II. Respects the Appalachian culture, including:

    A. Framing recommended practices in a way that Appalachian women connect with

    B. Using local "hosts" for programs from outside the region (such as mobile mammography units) to help Appalachian women feel more comfortable.

III. Addresses circumstances that Appalachian women see as obstacles to these practices. For example:

A. Being transparent about how services will be paid for

B. Considering logistical concerns (such as travel) in program development

Kreps (1993) discussed how health information is more likely to be followed if the patient has a good interpersonal relationship with his or her healthcare provider. However, this study found that not only does information from family and friends supersede information presented in mass media campaigns as McNeill and Dorgan (2004) found, but it also supersedes information presented in the clinical setting, which means that Appalachian women are more likely to believe information shared by family and friends than that shared by medical practitioners anyway. Health communicators must understand how to use the existing interpersonal relationships among Appalachian women to share information rather than attempting to recreate these relationships in the clinical setting. Understanding that Appalachian women are more likely to act on information they receive from interpersonal sources gives health communicators more opportunity to predict the behavior of Appalachian women.

Vanderpool and Coyne (2006) describe the role of intermediaries (such as local health department officials) in tailoring health messages outside the clinical setting to a local population. Women in this study made suggestions about how information could appeal more to women in the Appalachian area. For example, participants suggested that information be placed in more accessible locations, such as grocery stores and churches, which is congruent with suggestions from Simpson and King (1999). Health

communicators who are acting as intermediaries should be aware that health messages which include these components are more likely to be acted upon than those which do not. This information is especially useful for health communicators from outside the Appalachian region.

Finally, women in this study suggested that information about programs should be comprehensive. Lyttle and Stadelman (2006) found that cost and lack of insurance were the two main barriers to Appalachian women participating in community health programs. If information distributed to these women does not clearly address the main obstacles they perceive to participation, health communicators can expect lower participation. Distributing comprehensive information about breast health programs will also increase the ability of health communicators to predict how Appalachian women will participate in such programs.

Recommendations for Health Communicators

Participants in the current study favor moving breast health information out of the clinical setting and into more accessible community locations, such as churches, schools and shopping centers. Additionally, campaigns need to be designed to deliver information in ways that the target audience prefers. In the case of Claiborne County, women prefer information that is shared by word of mouth. Health programs from outside the region (such as mobile health units) need to include individuals from within the area as part of the staff to increase participation and trust.

Health communicators may also find it useful to review McGuire's (1989) 12-step hierarchy of effects to understand how to proceed with information campaigns in this

region. The hierarchy begins with exposure and awareness and ends with post-behavioral effects, where individuals incorporate particular messages into their world-views. Exposure and awareness can be fairly easy to accomplish (through media campaigns, for example), but long-term behavior change can take extended periods of time. McGuire (1989) noted that it gets easier to achieve effects at each level, but campaigns targeting the upper levels of the hierarchy without satisfying the lower levels first may be unrealistic. This study underscores the fact that many women in the region have met the first three steps on McGuire's hierarchy. Not only have these women been exposed to and made aware of breast health maintenance behaviors, but they also possess correct knowledge of these behaviors. Women in this study are currently in the attitude and belief stages of this model as some women in the region do not feel positively about breast health maintenance behaviors (attitude) and/or do not believe that these behaviors positively affect breast health. Until Appalachian women are persuaded to view breast health maintenance positively and believe that these behaviors lead to a positive outcome, they will not adopt these behaviors, which is the action step in McGuire's (1989) hierarchy. The move from belief to action is the most difficult transition on the hierarchy of effects so information campaigns need to move on from exposure and awareness to attitude and belief. Addressing these components as they relate to breast health will move women closer to taking preventive action that will improve their breast health.

The following findings are especially important to health communicators concerned with increasing early detection and reducing breast cancer mortality among Appalachian women:

- Participants trust women who are like them as sources of health information
- Participants see survivors as sources of health information
- Participants use the health experiences of family members and close friends to guide health decisions
- Participants possess correct knowledge about recommended breast health practices
- Participants are skeptical of outsiders

As a result, the following suggestions are made for health communicators:

- Breast health education should begin early (as part of school health programs) to normalize participation in recommended breast health practices and reduce embarrassment around the topic
- Mobile and "train the trainer" programs should be anchored to permanent programs within the community
- Women within the Appalachian area should be involved in the development of breast health campaigns in their counties
- Local churches should be used to promote preventive health messages
- Health messages should convey that participating in recommended breast health practices allow women to stay health and take care of their families
- Educational materials about breast health screenings should be placed outside the clinical setting in order to reach more women

- Breast health messages should feature survivors who benefitted from early detection

Suggestions for Future Research

The current study is the basis for additional studies related to Appalachian women and health, particularly health topics that affect women, such as other types of cancer (cervical, lung, and ovarian) and cardiovascular disease. Future research might include replication studies with Appalachian women from counties in other states to allow for comparison among different areas of the Appalachian region. Additionally, replication studies could focus on smaller age subgroups within the Appalachian population to allow for comparison among age subgroups. Future research should seek to better understand the role of technology, such as the Internet, in how Appalachian women obtain health information, as well as the sources of health information utilized and trusted by Appalachian women. Finally, future research should explore whether Appalachian men hold similar perceptions related to health issues that affect them.

Research Limitations

Findings in this study are limited by the fact that the researcher interviewed participants in one Appalachian county. This county may not represent the Appalachian region as a whole. Additionally, findings are limited by the extent to which participants answered truthfully the questions they were asked. Since the researcher found consistencies during the data coding process, she concluded that the participants were truthful. Because the researcher used a snowball technique to recruit participants, she was unable to meet with each participant to review a summary list of codes with each one.

However, the three participants she did meet with agreed that the summary lists of codes from all completed interviews reflected accurate outlines of their interviews.

Summary

This study defined four thematic constructs that explain how Appalachian cultural identity moderates perceptions about breast health: (1) The belief that breast health maintenance through recommended practices is important, (2) The belief that personal relationships impact breast health positively, (3) The belief that culture impacts breast health negatively, and (4) The belief that circumstance impacts breast health negatively. Health communicators can use these findings to better tailor their messages to Appalachian women. As a result, their campaign messages should (1) be built on interpersonal communication components, (2) respect the Appalachian culture, and (3) address circumstances that Appalachian women see as obstacles to these practices.

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Appendices

APPENDIX A

Health Rankings for Tobacco-Related Illnesses

	Ranking Out of 50				
State	**Smoking Tobacco Use**	**Cancer**	**Heart Disease**	**Heart Attack**	**Stroke**
Alabama	44	44	41	48	49
Georgia	21	24	13	19	16
Kentucky	50	50	49	49	45
Maryland	6	32	17	10	16
Mississippi	47	47	32	42	47
New York	24	8	29	10	23
North Carolina	36	35	36	33	35
Ohio	36	42	34	33	39
Pennsylvania	35	37	42	39	23
South Carolina	36	36	39	39	42
Tennessee	41	46	39	41	39
Virginia	32	31	8	19	10
West Virginia	49	49	50	50	47

Source: United Health Foundation. (2010). *America's health rankings—2010 edition*. St. Paul, MN: Author.

APPENDIX B

Health Rankings for Obesity and Diabetes

	Ranking Out of 50	
State	**Obesity**	**Diabetes**
Alabama	44	49
Georgia	28	38
Kentucky	47	47
Maryland	24	34
Mississippi	50	48
New York	10	31
North Carolina	39	39
Ohio	36	41
Pennsylvania	29	32
South Carolina	38	44
Tennessee	48	43
Virginia	16	22
West Virginia	45	50

Source: United Health Foundation. (2010). *America's health rankings—2010 edition*. St. Paul, MN: Author.

APPENDIX C

Verification of Informed Consent for Women

INFORMED CONSENT STATEMENT--WOMEN
Profiling How Women and Health Information Providers Define Breast Health in a Southern Appalachian Community

INTRODUCTION

You are invited to participate in a research study. The purpose of this study is to understand how women and health information providers in one Southern Appalachian community define breast health.

INFORMATION ABOUT PARTICIPANTS' INVOLVEMENT IN THE STUDY

You will participate in a face-to-face interview lasting approximately 45 minutes to an hour with the researcher. You will be asked about your understanding of breast health and about activities related to breast health.

Each interview will be audio recorded so the interview can be transcribed. Audiotapes of the interviews will be destroyed upon completion of the transcription. Direct quotations from participants may be used in the write-up of this study's results, but will not identify the participant.

RISKS

This study includes minimal foreseeable risk to you.

BENEFITS

Understanding how women and health information providers define and understand breast health will allow health communicators and educators to develop more culturally appropriate information campaigns and health interventions, which may reduce breast cancer morbidity and mortality in the Appalachian region.

CONFIDENTIALITY

Participant confidentiality will be maintained by separating the data from the informed consent form. Additionally, participants will not be referred to in the analysis by name or any characteristic that would make the participant easily identifiable. Participants will be allowed to choose a pseudonym or will be referred to descriptively in the analysis (i.e. 26-year-old female).

Only the researchers will have access to the interview tapes and transcriptions. Tapes of the interviews will be destroyed upon completion of transcription. Interview transcripts will be maintained for five years in a locked office in the home of the researcher. Transcripts will then be shredded.

_____ Participant's initials

CONTACT INFORMATION

If you have questions at any time about the study or the procedures, you may contact the researcher, Hannah Shinault, at 276-920-1552 or hshinaul@utk.edu. If you experience any adverse effects from participating in this study, please contact your family doctor or Claiborne County Hospital at 423-626-4211. If you have questions about your rights as a participant, contact the Office of Research Compliance Officer at (865) 974-3466.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at anytime without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed you data will be returned to you or destroyed.

CONSENT

I have read the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature _____ Date _____

Investigator's signature _____ Date _____

APPENDIX D

Informed Consent for Providers

INFORMED CONSENT STATEMENT--PROVIDERS
Profiling How Women and Health Information Providers Define Breast Health in a Southern Appalachian Community

INTRODUCTION

You are invited to participate in a research study. The purpose of this study is to understand how women and health information providers in one Southern Appalachian community define breast health.

INFORMATION ABOUT PARTICIPANTS' INVOLVEMENT IN THE STUDY

You will participate in a face-to-face interview lasting approximately 45 minutes to an hour with the researcher. You will be asked about the type of breast health information you provide to women.

Each interview will be audio recorded so the interview can be transcribed. Audiotapes of the interviews will be destroyed upon completion of the transcription. Direct quotations from participants may be used in the write-up of this study's results, but will not identify the participant.

RISKS

This study includes minimal foreseeable risk to you.

BENEFITS

Understanding how women and health information providers define and understand breast health will allow health communicators and educators to develop more culturally appropriate information campaigns and health interventions, which may reduce breast cancer morbidity and mortality in the Appalachian region.

CONFIDENTIALITY

Participant confidentiality will be maintained by separating the data from the informed consent form. Additionally, participants will not be referred to in the analysis by name or any characteristic that would make the participant easily identifiable. Participants will be allowed to choose a pseudonym or will be referred to descriptively in the analysis (i.e. 26-year-old female).

Only the researchers will have access to the interview tapes and transcriptions. Tapes of the interviews will be destroyed upon completion of transcription. Interview transcripts will be maintained for five years in a locked office in the home of the researcher. Transcripts will then be shredded.

_____ Participant's initials

CONTACT INFORMATION

If you have questions at any time about the study or the procedures, you may contact the researcher, Hannah Shinault, at 276-920-1552 or hshinaul@utk.edu. If you experience any adverse effects from participating in this study, please contact your family doctor or Claiborne County Hospital at 423-626-4211. If you have questions about your rights as a participant, contact the Office of Research Compliance Officer at (865) 974-3466.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at anytime without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed you data will be returned to you or destroyed.

CONSENT

I have read the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature _____ Date _____

Investigator's signature _____ Date _____

APPENDIX E

Discussion Guide for Women

1. Please tell me a little about yourself.

2. Tell me what it means to you or what you know about breast health.

    Is breast health part of your daily life?

    When was the last time you thought about breast health?

    Does faith influence how you think about breast health?

    Family?

    Environment?

3. What is good breast health?

4. Tell me what you do (if anything) to maintain good breast health.

    What do your friends/family do for breast health?

    Is it important for women to care about their breast health?

5. Where do you get information about breast health?

6. Do you know anyone who has had breast cancer (close friend, relative, etc.)?

    Did you learn anything related to breast health from that person's experience?

7. Do you feel that there is enough information about breast health in the community?

8. Are you aware of programs about breast health within the community?

9. If we wanted to get information out to every woman in the community, where should we put it?

10. Do you think women prioritize their health?

APPENDIX F

Discussion Guide for Providers

1. Please tell me a little bit about yourself.

2. Tell me what it means to you or what you know about breast health.

3. Tell me what it means to have good breast health.

4. What information do you give women about breast health?

5. What should women do to maintain good breast health?

6. What are your impressions of breast health in Claiborne County?

APPENDIX G

Alphabetical List of Open Codes

Adequate information: P6, P7, P8, P9, P11, P12, P22, P27, P32, PN, PRT
Breast health is important: P14, P20, P27, P32
Breast health is influenced by family: P20
Breast health is the absence of disease: P1
Breast health means no breast cancer: P21, P24, P27, P28
Breast health means no physical abnormalities: P11, P14, P28, P31
Breastfeeding is stigmatized: P10, P14, P24
Breasts are taboo: P10, P14, P20, P23, P27, P29
County residents get less info: P3, P13, P14, P19, P27
Drugs are prevalent: P9, PN
Elderly women are less likely to go to the doctor: P5, P21, P32
Environment detracts from health: P14, P21, P31
Faith as a substitute for medical care: PRT
Faith helps health generally: P6, P11, P13, P14, P25, P27, P31, P32
Faithful people experience better health outcomes: P12, P27
Family encourages maintenance: P14, P20, P27
Family helps understand risk: P8, P15, P21, P23
Family is a support system: P12, P32
Family provides motivation: P8, P20, P21, P23A, P30
Fear of following up on health issues: P11, P20, P27
Female providers are better: P3, P6, P8, P13, P14, P20, P22, P25, P30, PRT
God and prayer influence health positively: P5, P13, P19, P23, P29
God works though doctors: P10, P25, P28
Good breast health is maintained by going to the doctor: P12, P13, P20, P32
Good breast health is maintained through diet: P6, P20, P21, P19
Good breast health is maintained through mammograms: P11, P12, P20,
Good breast health is maintained through self-exams: P11, P12, P13, P20
Good breast health means access to information: P19
Health education is inadequate: P15, P30, P31, PG, PRT
Health issues are ignored: P2, P10, P12, P31
Health is private: P20, P22, PMED, PRT
Husbands deter gynecological care: P21, P25
Ignorance of how to address health issues: P7, P20, P32, PG, PRT
Inadequate information: P7, P8, P12, P13, P14, P15, P19, P20, P21, P28, P30, P31, PMED
Internet is source of info: P6, P7, P10, P23A
Irregular maintenance behavior: P6, P22, P28, P32
Lack of insurance detracts from health: P1, P7, P9, P11, P14, P21, P25, P31, PMED, PG
Lack of interest in disease causes: PMED

Lack of money detracts from health: P7, P9, P14, P19, P20, P22, P25, P28, P32, PMED, PRT
Local physicians are better: P6, P22
Magazines are source of info: P1, P14
Male providers are better: P28, P29
Medical professionals are most trusted source of info: P1, P7, P8, P9, P12, P13, P14, P15, P21, P21, P22, P23, P23A, P24, P25, P27, P28, P29, P30, P31
Non-local physicians are better: P3, P7, P19, P23A, P32
Oak Ridge: P4, P5, P7, P13, P19, P20, P21, P22
Outsiders get less info: P3, P6, P7, P14
Outsiders treat Appalachians like hillbillies: P2, P7, P8, P12, P13, P14, P15, P19, P21, P27, P31, P32
People are set in their ways: P13, P25, P30
Physicians are bad listeners: P3, P6, P14
Preventive measures are not common: P11, P12, P15, P19, PN, PMED, PRT
Poor women do not have access to information: P2
Putting off medical care: PN, PMED
Recommendation: Leave health info with churches: P11, P29, P30, P31,
Recommendation: Provide info about sliding scale fees: P14
Recommendation: Provide more visual materials for mammograms: P7, P23A, P25
Recommendation: Provide open house tours for mobile mammography: P7
Recommendation: Put breast health info at social services: P2
Recommendation: Put breast health info in grocery stores: P9, P15, P19, P20, P21, P22, P23, P32,
Recommendation: Put breast health info in health department: P11, P14, P25
Recommendation: Put breast health info on a billboard: P13, P15, P24, P28
Recommendation: Send breast health reminders home with kids: P7
Reluctance to visit physician: P14, P22, P23A, PN, PRT
Skeptical of medical advice: P6, P7, P14, P20
Smoking is bad for health: P32
Specialists are better than GPs: P2, P9, P10, P15, P20, P21, P23A, P27, P29
Survivors as a source of information: P12, P23A, PN, PRT,
Survivors encourage maintenance behavior: P7, P11, P20, P21, P27
Survivors illustrate seriousness: P1, P12, P23, P30
Survivors provide coping strategies: P13, P19, P23, P28
Survivors provide technical knowledge: P8, P11, P14, P15, P25
Survivors raise awareness: P10, P15, P23, P23A, P24
Television is a source of info: P1, P6, P12, P13, P15, P27, P29
Travel is costly: P13, P14, P19, P21, P25, P27, P30
Travel is difficult: P13, P14, P19, P25, P30
Women don't prioritize health: P7, P19, P21, P22, P23, P23A, P24, P25, P27, P28, P29, P30, P31, PRT
Word of mouth: P2, P7, P8, P12, P13, P14, P15, P19, P21, P27, P31, P32

APPENDIX H

Outline of Categories and Subcategories

I. The Belief that Breast Health Maintenance Through Recommended Practices is Important (Selective Code)
- A. Good Breast Health (Axial Code)
  1. Breast health is important (open code)
  2. Breast health is the absence of disease (open code)
  3. Breast health means no breast cancer (open code)
  4. Breast health means no physical abnormalities (open code)
  5. Good breast health is maintained through diet (open code)
  6. Good breast health means access to information (open code)
- B. Recommended Practices (Axial Code)
  1. Good breast health is maintained by going to the doctor (open code)
  2. Good breast health is maintained though mammograms (open code)
  3. Good breast health is maintained through self-exams (open code)
  4. Irregular maintenance behavior (open code)

II. The Belief that Personal Relationships are Important to Breast Health (Selective Code)
- A. Relationship with God (Axial Code)
  1. Faith as a substitute for medical care (open code)
  2. Faith helps health generally (open code)
  3. Faithful people experience better health outcomes (open code)
  4. God and prayer influence health positively (open code)
  5. God works through doctors (open code)
- B. Relationships with family (Axial Code)
  1. Breast health is influenced by family (open code)
  2. Family encourages maintenance (open code)
  3. Family helps you understand risk (open code)
  4. Family is a support system (open code)
  5. Family provides motivation (open code)
- C. Relationships with survivors (Axial Code)
  1. Survivors are a source of information (open code)
  2. Survivors encourage maintenance behavior (open code)
  3. Survivors illustrate seriousness (open code)
  4. Survivors provide coping strategies (open code)
  5. Survivors provide technical knowledge (open code)
  6. Survivors raise awareness (open code)

III. The Belief that Culture Detracts from Good Breast Health (Selective Code)
- A. Women don't prioritize their health (Axial Code)
  1. Elderly women are less likely to go to the doctor (open code)
  2. Husbands deter gynecological care (open code)
  3. Women don't prioritize health (open code)
- B. Attitudes about health (Axial Code)

1. Fear of following up on health issues (open code)
2. Health issues are ignored (open code)
3. Ignorance of how to address health issues (open code)
4. Lack of interest in disease causes (open code)
5. People are set in their ways (open code)
6. Preventive measures are not common (open code)
7. Putting off medical care (open code)
8. Skeptical of medical advice (open code)

C. Attitudes about doctors (Axial Code)
1. Female providers are better (open code)
2. Local physicians are better (open code)
3. Male providers are better (open code)
4. Non-local physicians are better (open code)
5. Physicians are bad listeners (open code)
6. Reluctance to visit physicians (open code)
7. Specialists are better than GPs (open code)

D. Modesty (Axial Code)
1. Breastfeeding is stigmatized (open code)
2. Breasts are taboo (open code)
3. Health is private (open code)

E. Attitudes about Outsiders (Axial Code)
1. Provide open house tours for mobile mammography (open code)
2. Outsiders treat Appalachians like hillbillies (open code)

IV. The Belief that Circumstance Detracts from Good Breast Health (Selective Code)

A. Financial Factors (Axial Code)
1. Lack of insurance detracts from health (open code)
2. Lack of money detracts from health (open code)

B. Travel (Axial Code)
1. Travel is costly (open code)
2. Travel is difficult (open code)

C. Environment (Axial Code)
1. Environment detracts from health (open code)
2. Oak Ridge (open code)

D. Education (Axial Code)
1. Health education is inadequate (open code)
2. Send breast health reminders home with kids (open code)

E. Access to Information (Axial Code)
1. Adequate information is available (open code)
2. County residents get less information (open code)
3. Inadequate information available (open code)
4. Internet is a source of information (open code)
5. Magazines are a source of information (open code)
6. Medical professionals are the most trusted source of health information (open code)

7. Outsiders get less information (open code)
8. Poor women do not have access to information (open code)
9. Leave health information with churches (open code)
10. Provide information about sliding scale fees (open code)
11. Provide more visual materials for mammograms (open code)
12. Put breast health information at social services (open code)
13. Put breast health information in the grocery store (open code)
14. Put breast health information in health department (open code)
15. Put breast health information on a billboard (open code)
16. Television is a source of information (open code)
17. Word of mouth is the best way to share information (open code)

F. Lifestyle Factors (Axial Code)
    1. Drugs are prevalent (open code)
    2. Smoking is bad for health (open code)

Vita

Hannah Leigh Shinault was born in Wytheville, Virginia, the oldest daughter of Diane Ivins and Preston Shinault. After graduating from George Wythe High School in 2002, she earned a Bachelor of Arts degree in Media Arts and Design from James Madison University in 2005. Hannah continued her academic career at Radford University, where she taught public speaking. After finishing her Masters degree in 2008, Hannah pursued a doctoral degree in Communication and Information at the University of Tennessee. Her primary concentration was public relations with a secondary concentration in public health. Her research interests include Appalachian/rural health, cancer and women's health communication. Hannah is an active member of the National Communication Association and the American Public Health Association. Currently, she is an instructor at Virginia Tech in Blacksburg, VA.