

AFRICAN-AMERICAN WOMEN'S BELIEFS ABOUT THE INTERNET AS A SOURCE OF
BREAST CANCER PREVENTION INFORMATION

By

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Abstract of Dissertation Presented to the Graduate School
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Although African-American women are less likely to be diagnosed with breast cancer than Caucasian women, the mortality rate for African-American women with breast cancer is higher. Part of the effort to reduce this disparity includes education about prevention and early detection.

The Internet has become a popular source of information for people who seek to know more about health topics. The medium can be a vehicle to disseminate general prevention information to the public and tailored information to subgroups. However, the literature reveals little about if, why, and how African-American women who do not have breast cancer seek out prevention information.

This project is a mixed methods study of African-American women's beliefs about breast cancer prevention and attitudes about looking for prevention information on the Internet. Specifically, the research sought to discover if beliefs about the disease or beliefs about the medium related to a woman's online prevention information-seeking.

The study included in-depth interviews with nine African-American women without personal histories of breast cancer and 160 written surveys developed based on the interview results. Variables of particular interest were family history of breast cancer and Internet use.

Participants included a mix of women with and without family histories of breast cancer, as well as low and high users of the Internet.

Inferences about the relationships between these variables were based on analyses of both qualitative and quantitative data. Internet non-use seemed to be more related to physical access to the medium than to beliefs about the medium. Seeking behavior among women with Internet access was related to beliefs about personal risk of the disease. Results indicate that family history is overwhelmingly thought to put a woman at risk for developing breast cancer. Women who do not have this family history may be unlikely to seek information about preventing the disease. The implications of this finding are that breast cancer primary prevention interventions targeting women without family histories of breast cancer should aim to increase women's knowledge about the disease's risk factors and emphasize the women's need to be proactive in prevention behaviors.

CHAPTER 1 INTRODUCTION

Healthy People 2010 (United States Department, n.d.), the federal government's written plan for improving the nation's health and setting goals to achieve by the year 2010, recognizes that the health of citizens and residents of the United States has been improving or maintaining for some subgroups in the population while others lag behind in health status. The document points out the need to reduce disparities that exist in the health of different demographic groups. Breast cancer among African-American women represents one health disparity. Despite the fact that, in general, breast cancer mortality rates are relatively low compared to those of other cancers, there are race differences in death rates from the disease. African Americans are less likely to be diagnosed with breast cancer, but those with the disease are more likely to die from it than their white peers. The Healthy People 2010 objective is to reduce age-adjusted mortality due to breast cancer in African-American women from 35.1 (per 100,000) in the baseline year of 1999 to 21.3 by 2010 (Centers for Disease Control, 2007). In 2005, the half-way mark of Healthy People 2010 and the most recent year for which data was found, mortality rates for African-American women with breast cancer were slightly lower at around 33 (per 100,000) than the baseline but not close to the targeted rate (CDC, 2009a).

While science has not yielded conclusive answers as to what causes breast cancer in its many forms, there are some identified risk factors that women should know, including inherited genetic and behavioral characteristics. Some of these factors are characteristics over which individuals exercise little control. However, some research suggests that overall healthy behaviors may have a protective effect, including not smoking, limiting alcohol consumption, exercising regularly and eating a nutritious diet (McPherson, Steel, & Dixon, 2000).

A growing body of research now demonstrates that the majority of American adults use the Internet (Fox, 2006), and one of the most common online activities is seeking information about health, including chronic diseases such as breast cancer. At the time of this paper's writing, the medical community could not tell women what women can do to prevent breast cancer; there are no clear answers. However, science's lack of definitive answers likely will not forestall people's efforts to seek information on ways to prevent breast cancer. Even though the present study's purpose is not to investigate factors believed to cause breast cancer, including those related to unhealthy behaviors (obesity and overweight, tobacco consumption, etc.), it does suggest that having more people engage in positive behaviors will reduce the effect of breast cancer (Miller, 1995). In addition, although screenings for breast cancer, including mammography, are not considered primary prevention methods, mammography and other secondary prevention methods are often discussed as prevention options for women with no personal histories of breast cancer.

The purpose of this study, therefore, will be to add to our understanding of the social, cultural, and even individual level determinants of whether or not a woman uses the Internet to seek breast cancer information. An ultimate goal of this line of research would be to find out more about the most likely users of an online breast cancer information resource so that Web sites and other interventions can be developed to serve these women most effectively. Using in-depth interviews and surveys, the project explored women's beliefs about breast cancer, their intentional seeking of breast cancer prevention information from any source, their attitudes about and use of the Internet in general, and, linking these concepts, the women's attitudes about and use of the Internet for breast cancer prevention information. The phrase "beliefs about the Internet" will be used throughout this paper to refer to women's beliefs about the value of the Internet as a health information source as well as beliefs about their ability to use the Internet

successfully to obtain information. The latter is a form of self-efficacy, which Bass and colleagues refer to as “confidence in being able to complete a task” (2006, p. 221). Primary and secondary breast cancer prevention are both considered in this study’s literature. Other screening methods, such as genetic testing, could be included as factors in secondary prevention because some participants had family histories of breast cancer (or as primary prevention, if women opt for prophylactic mastectomies based on genetic tendencies toward the disease), but for this study, mammography, as a very common and emphasized screening for women older than age 40 (American Cancer Society, 2007d), was the main representation of secondary prevention.

The remainder of this chapter will discuss the epidemiology of breast cancer, the different levels of breast cancer prevention, and how breast cancer has become a “cause,” therefore gaining a great deal of media attention over the years. Chapter 1 also introduces Newhagen and Bucy’s (2004) new media content access model, which organizes this study’s exploration and explains the study’s research questions.

In Chapter 2, prior research is presented about the health beliefs and potential barriers to enacting healthful behaviors in some African-American cultures and communities. Relevant literature about health and breast cancer information-seeking, as well as Internet use in general, is reviewed. Chapter 3 describes the methods used for analyzing the relationship between African-American women’s individual characteristics, their use of the Internet in general, and their use of the Internet for breast cancer prevention information. The findings of the in-depth interviews and surveys used for data collection are discussed in Chapter 4, and Chapter 5 reports on and discusses the study conclusions.

Breast Cancer & Prevention

Of all diseases that affect women, breast cancer is most feared, even though the disease claims fewer women’s lives than does heart disease (Wider, 2005). Breast cancer is not even the

most deadly cancer among women; that distinction belongs to lung cancer (ACS, 2007a). However, a Google search for lung cancer produces 2.3 million results, compared to the 7 million Web pages found in a search for breast cancer. Perhaps this is a reaction to demand: searches for breast cancer information are more common than searches for lung and prostate cancer information (Metz, Devine, et al., 2003). Media, grass roots movements, and the fact that breast cancer affects women in an intimate way also may contribute to the disease's inflated attention. As breast cancer continues to occupy a prominent place in medical research and funding advocacy, it will remain a popular topic for Web sites.

The American Cancer Society's forecast ranked breast cancer as the number one site of new cancer cases in women in 2007 and the second most deadly (ACS, 2007a). In African-American women specifically, breast cancer was predicted to account for 27% of new cancer cases in 2007 and 19% of deaths from cancer (ACS, 2007b). Although deaths from breast cancer fell slightly among white women from 1975-2003, for African-American women, mortality rates from the disease were a few percentage points higher in 2003 than in 1975.

Breast cancer has one of the highest five-year survivorship rates of all cancers, likely the result of awareness efforts and early detection initiatives. The United States showed a 33.8 (per 100,000 people) death rate of African-American women from breast cancer during the 2000-2004 period (ACS, 2008); among African-American women in Florida, the rate was slightly better at 30.7 (ACS, 2007b). In comparison, the death rate nationwide (per 100,000 people) among White women for the same period was 25 (ACS, 2008).

Although the term "breast cancer" is commonly used in the singular, in reality it represents different types of cancer that affect the breast. The anatomical site is the same for these diseases, but their etiologies, manifestations, and treatments vary. Breast cancers develop when cells in the

breast begin to grow abnormally. Usually cells in the human body go through a cycle of dying and being replaced by new cells that know how to function properly in their places. However, cells that grow incorrectly form tumors, and malignant tumors that begin to spread, or metastasize, to surrounding tissues threaten to interfere with vital body functions. This is, in essence, breast cancer (National Cancer Institute, 2005b). Breast cancer is much more common in women than in men (ACS, 2008), which is why women have rallied to support research to eradicate the physical and emotional suffering caused by the disease.

Breast Cancer Risk Factors

There are many identified risk factors for developing breast cancer, some of which are related to controllable behaviors and lifestyle choices and others that are associated with inherited genes. As Teolis points out, however, being female and aging are the most predictive of risk factors for breast cancer (2004). Experts believe that smoking, excessive alcohol consumption and lack of exercise may increase a person's risk of developing breast cancer. Family histories of breast cancer and such personal factors as when a woman goes through menarche and reaches menopause have been shown to relate to a higher chance of breast cancer. Additionally, a woman's risk of breast cancer goes up as she ages (NCI, 2005b). Scientists have identified several genes that are related to breast cancer risk. The BRCA 1 and BRCA 2 genes are risk factors for breast cancer, although scientists caution that a low percentage of breast cancer cases occur among women with these genes.

The concept of prevention typically is divided across three levels in public health practice, each with a different focus and goal. Primary prevention efforts aim to promote healthful behaviors and services in communities so that certain health problems do not develop. Turnock describes primary prevention as "strategies that seek to prevent the occurrence of disease or injury, generally through reducing exposure or risk factor levels. These strategies can reduce or

eliminate causative risk factors (risk reduction)” (2004, p. 398). To reduce the risk of breast cancer, at the primary level, women are encouraged to eat healthful foods, to abstain from smoking and excessive alcohol use, and to get adequate physical activity. The hope is that such actions will reduce the number of breast cancer cases that occur. Targeted groups in an intervention are those which are considered susceptible to the health problem but do not currently have it, so that incidence reduction is the ultimate goal. This includes women who may be helped by taking chemoprevention therapies, such as tamoxifen, or undergoing prophylactic mastectomies (Chen, Rosner, & Colditz, 2007; Cummings, 2007). Naturally, primary prevention is the desired level of public health interventions. They are the most cost-effective in terms of outcomes (Turnock, 2004), and they maximize quality of life in the targeted individuals.

Secondary prevention programs focus on identifying health problems in early stages through the use of screenings and other tools. Detecting illnesses at this point, it is believed, will make them easier to treat and will reduce symptoms and mortality, protecting some measure of patients’ quality of life (Turnock, 2004). Prevention at the secondary level calls for diligent screening and testing so that breast cancer cases will be detected early, at stages enabling the most effective treatment. The mammogram is the most common medical diagnostic tool for detecting breast cancer, and it is generally recommended that most women have one annually after they reach age 40. Before that age, clinical exams should be included in yearly gynecological appointments for women (ACS, 2007d). Yabroff found that mammography is associated with “improved survival, lower annual costs of care, and lower continuing care costs” than later detection (2000, p. 208). Evidence suggests mammograms can detect breast tumors at earlier stages than usually identified in clinical or self-examinations (Elmore, et al., 2005).

The final level is tertiary prevention. This one involves treating individuals with later stages of a disease. It usually requires specialist medical teams and more invasive techniques, with the goal being preventing death and morbidity. Strategies for breast cancer at this level include various treatments like radiation, chemotherapy, hormone therapy, mastectomy and lumpectomy. These treatments, which differ by degree of invasiveness, may be used in combinations as part of an aggressive treatment effort. According to the American Cancer Society (ACS), the five-year survival rate for breast tumors detected and treated at stages 0 and 1 is 100%.¹ Later stage tumors that may be larger and have spread to other parts of the body have lower five-year survival rates, from 93% for stage IIA to 20% for tumors detected at stage IV (ACS, 2007c).

History of the “Cause”

The proliferation of Web sites about breast cancer is likely due, at least in part to increases in the number of awareness campaigns and the intense media focus on the issue. Braun (2003) credits an emphasis on breast health and more media attention to breast cancer victims’ stories in the early 1980s with raising awareness of breast cancer as a critical public health problem. The media effectively “plac[e] and maintain health issues on the public agenda” and provide “straightforward information” (Downie, et al., 1996, p. 32). Whether the media focus first raised consciousness of the disease or the awareness campaigns captured media attention, the point is that breast cancer awareness in all its forms (research for a cure, prevention education, and patient support) has become a recognizable cause.

¹ The National Cancer Institute describes breast cancer stages 0-IV. Very generally, stage 0 is breast carcinoma in situ, where abnormal cells are in the breast lining but they have not spread beyond that location. On the other end of the breast cancer spectrum, patients at stage IV have cancers that have spread to other body organs. Stages in between those two extremes reflect increasing tumor size, cancerous activities in the lymph nodes, and metastasis to other body parts (NCI, 2009a).

October is national Breast Cancer Awareness Month in the United States. During this month, and indeed year-round, many individuals wear or display pink ribbons or pink ribbon symbols, which are meant to raise awareness of the disease. Organizations like the Susan G. Komen for the Cure foundation and the American Cancer Society have educational programs and event fundraisers designed to honor those who have died from breast cancer, to support breast cancer patients and survivors, and to raise money for research and cure-related initiatives. The pink ribbon has become a widely recognized symbol of the collective movement to develop treatments and eventually find a cure for breast cancer.

No studies could be found showing the extent to which the public associates the pink ribbons with breast cancer causes. However, the sheer number of commercial enterprises seeking to align themselves with the breast cancer awareness and cure cause indicates that this associative relationship is very strong (Orenstein, 2003; Jackson, 2006). Some companies offer to donate portions of purchase proceeds to a breast cancer charity in exchange for the positive association with the cause (Till & Nowak, 2000). Advertisements in the media show that alignment with the cause crosses industries, with companies like Ford Motor Company, Oreck Corporation (vacuum cleaners), and the Avon cosmetics company forming partnerships with breast cancer organizations and sometimes establishing their own fundraising foundations.² Another indication of the successful breast cancer awareness month initiative is the increase in the number of mammograms performed during October each year (Effect of breast cancer, 2005).

One positive effect of the media attention devoted to breast cancer causes may be increased awareness of the disease. Women who have information about breast cancer

² See Ford's "Warriors in Pink" campaign (<http://www.fordvehicles.com/>), Oreck's "Clean for the Cure" (<http://www.oreck.com>), and Avon's foundation (<http://walk.avonfoundation.org/>).

prevention methods, including good diet and exercise at the primary prevention level and compliance with recommended screenings at the secondary prevention level, may be able to make changes in their lives to lessen their risks of developing breast cancer or detecting the disease at a late stage. Not only is the idea of reducing cancer risk advantageous to the individual women and their families who would be spared the pain and emotional effects of the disease, these types of prevention are economically ideal for the nation. Population-based and primary prevention efforts are better investments in public health than are tertiary care plans.

This logic supports the idea that the Internet should serve as a medium for providing women with information they can use to reduce their risks of developing breast cancer.³ It may especially serve as a resource for women, including many African-American women, who face disadvantages in regular access to the health service system (Gustafson, et al., 2005). However, there appears to have been no published research specifically exploring whether and how African-American women who have not been diagnosed with breast cancer use the Internet to find information about preventing the disease. Several studies have examined how African-American women with breast cancer (or with personal histories of breast cancer) use the medium (e.g. Fogel, Albert, et al., 2002; Talosig-Garcia & Davis, 2005). There are also studies about how African-American women construct beliefs about breast cancer and prevention tools such as mammography (Beckjord & Klassan, 2008; Russell, et al., 2007). Findings from these and other related areas of scholarship about breast cancer will be discussed in the following sections of this paper. They fall into categories of health and Web literacy, access to the Internet, and perceived benefit from online breast cancer information. Such studies allow us to explore aspects of the

³ Clearly this is a simplistic line of reasoning that in no way assumes that information receipt will translate into behavior change. As this paper suggests, the literature on how certain subpopulations make use of this online prevention content has not been established. How that content impacts behavior is an additional step in the research that cannot be made until the immediate questions are answered.

online breast cancer experience in depth and then assemble them into a larger picture. However, it remains to be seen whether this reductionist approach to understanding how women use the Internet for breast cancer information really captures that experience in a way that can be used to improve how organizations present and deliver breast cancer information through the medium. Furthermore, it is unclear if and how the prevailing public health paradigm of multiple determinants has been married to a modern theory of new media use in a way that provides an agenda for future research in this area.

Through the literature review and study methods, this project seeks to raise several issues for discussion in the health communications research forum, in addition to answering specific research questions that will be presented later in the document. The contentions, starting from a micro research perspective and extending to the macro, are that use of the Internet for breast cancer information by a woman who has been diagnosed with the disease will likely be different from the medium's use by women who have no personal history of breast cancer. If this is true, then the plethora of findings about how African-American breast cancer patients or survivors use the Internet offers limited insight into prevention information-seeking. The second point is that ecological studies about how the Internet has diffused across race, gender, education level and income groups tell us only about physical access to the technology, not how the users construct meaning from the content they find.⁴ In other words, even if two people are provided the same Web site about breast cancer prevention, they likely will interpret the content differently because they employ unique cognitive abilities, life experiences, socially constructed meanings about disease, and other filtering variables. Neither of these ideas is new. Theories such as the Health Belief Model (Janz, Champion & Strecher, 2002) include variables such as perceived

⁴ Of course this is not the stated purpose of such studies.

susceptibility to a health problem as influences on how people attend to health messages and adopt behaviors. A breast cancer diagnosis naturally increases someone's perceived vulnerability to breast cancer. Likewise, theories suggest that individuals' understanding and behavior are mediated by social, cultural and community influences.⁵ Where the existing literature fails to offer non-assumptive questions is at the intersection of these influencers on both Internet use and conception of personal health at a meaning level. In other words, we cannot know how African-American women without breast cancer use the Internet for breast cancer information based on the literature that has focused on women with the disease. Also, we cannot know if African-American women's use (or non-use) of the Internet for such educational material is related to their beliefs about the Internet being a good or bad source for breast cancer information or their beliefs about preventing breast cancer.

The ultimate idea upon which this study's thesis rested was that there may be something unique about African-American women's perceptions of breast cancer prevention and intention to seek information about it; and there may be something unique about African-American women's use of the Internet and the ways in which they interpret online content. The answer to the question of how and why African-American women use and create meaning from Internet information about breast cancer prevention may not be the sum of the two parts. Results from studies of how African-American women conceptualize breast cancer prevention and studies of how African-American women use the Internet may not tell us how African-American women use the Internet for breast cancer prevention information.

⁵ For example, Heaney and Israel (2002) explain the role of social networks on people's health. Baranowski, Perry and Parcel (2002) describe how Bandura's Social Cognitive Theory relates to interpersonal influences on individuals' health.

Although published studies about how breast cancer patients and survivors use the Internet for information about (and for coping with) the disease are numerous (e.g. Rees & Bath, 2001; Williamson, 2005; Dickerson, et al., 2006; Ziebland, Chapple, et al., 2004; Eysenbach, 2003), the body of literature exploring how women without personal histories of breast cancer use the Internet for prevention information is scarce. A rather obvious explanation for this is that perhaps such women do not seek breast cancer prevention information, so such studies would be unnecessary. If women do not believe that they are at high risk for breast cancer, they may not be prompted to enact the health behavior of prevention information-seeking. As stated before, however, clearly a breast cancer diagnosis should increase a woman's perceived personal susceptibility to the disease and change her behavior, including information-seeking and use of the Internet for other breast cancer purposes.⁶

Using the Web to find out about treatments or to join an online support group are two examples of how women with breast cancer utilize the technology. Such activities may contribute to a woman's psychological, emotional and physical survival during and after treatment, thus warranting their placement on a list of secondary or tertiary prevention tools. As described earlier, secondary prevention in public health includes efforts aimed at detecting health problems like breast tumors early so that they can be treated in less invasive ways.

Mammography and other screenings fall into this category. Tertiary prevention involves efforts to reduce mortality and morbidity from the disease, the latter of which will be discussed later.

These are important in the planning of breast cancer mortality and morbidity prevention strategies. However, it is a goal of primary public health interventions to reduce the incidence of

⁶ For example, Satterlund, McCaul and Sandgren (2003) found that for women who had been diagnosed with breast cancer, patterns of Internet use for information about the disease changed as they progressed through stages of treatment and recovery. From this we might surmise that a similar difference in health information-seeking might be found before a breast cancer diagnosis.

breast cancer in the population. Although there is no known guaranteed way to avoid getting breast cancer, taking suggested steps to reduce one's chance of developing the disease, such as not smoking, may do more than just prevent death. Women with advanced stages of breast tumors experience higher rates of depression, anxiety and other psychiatric issues as they deal with the disease and its consequences (Grabsch, et al., 2006). But women at other stages of breast cancer also may face psychological and physical side effects from the ordeal, treatment, and living with possibility of recurrence (Wilmoth & Sanders, 2001), affecting their quality of life. These types of morbidity issues are associated with tertiary prevention.

Compared with women who have not had breast cancer, survivors of the disease report lower quality of general health (Paskett, 2008) and a reduced quality of life from their pre-cancer states (Michael, et al., 2000). In addition to general health concerns, women with breast cancer may suffer fatigue and experience difficulty concentrating as side effects of treatments (Ashing-Giwa, et al., 2004). Other physical side effects of breast cancer treatments are hair loss from chemotherapy and arm and chest swelling (lymphedema) resulting from disruption to the lymph system from breast surgery and radiation (ACS, 2009a). Decreased sexual desire has also been reported in post-treatment women (Ashing-Giwa, et al., 2004).

Physical effects of breast cancer treatment and survival may impact women's psychological and emotional well-being, too. Mastectomy, which involves removing the breast, may result in specific concerns for African-American women who are more prone to forming keloid (cell overgrowth) scars and may worry about finding prosthetics that match their skin tone (Wilmoth & Sanders, 2001). Women, especially young survivors, may experience body image issues, possibly believing they are not as attractive as they once were (Ashing-Giwa, et al., 2004; Fobair, et al., 2005). And women from ethnic and racial minorities may report embarrassment for

having the disease and concerns about discrimination in the medical system affecting their care (Ashing-Giwa, et al., 2004).

For these reasons it is important to stress prevention for women who have not been diagnosed with breast cancer, and that aim is one of the key foundations of this project. It is also important for researchers, medical professionals and others involved in looking into the future of cancer prevention to better understand the tools and opportunities for public health education available through new media.

Cultural Sensitivity

Providing culturally sensitive health interventions and services may help reduce some of the health disparities that affect minority residents in the United States (Office of Minority Health, 2005). Developing cancer prevention information that is more culturally relevant to subpopulations may increase the perceived personal relevance of that information to individuals in those groups because ideas about health well-being vary across cultural groups (Friedman & Hoffman-Goetz, 2006; Guidry, Fagan, & Walker, 1998). For example, African Americans may prefer to have their race and culture considered in the cancer information they receive, including cancer statistics and risk calculations (Brown & Williams, 1994).

Cultural sensitivity is an often ill-defined term that refers to incorporating understanding of, and elements from, a target population's culture or experience, including customs, language, and values, into health interventions (Office of Minority Health, 2005). According to one explication of the term, cultural sensitivity includes both congruence between the health message content – in terms of language and appearance – and the message receiver's culture, and the understanding that the receiver's culture affects her health perception and behavior (Friedman & Hoffman-Goetz, 2006).

Culturally sensitive interventions are based on the idea that audience members may have distinct culturally-formed and maintained expectations about health behaviors that should be addressed in order for interventions to be effective. Research suggests that encouraging health behavior adoption, such as getting mammograms, in African-American women “requires understanding the concept of ‘culture,’ a patterned way of life that has special meaning to the individual and his or her social group” (Bailey, Erwin, & Belin, 2000, p. 136). The cultural sensitivity literature suggests that health information must take into account audiences’ beliefs (including knowledge, attitudes, and values), barriers and “enablers” to enacting change, and the mediation of beliefs and activities by individuals’ peer and social spheres (Kline, 2007). Culturally sensitive materials and interventions may identify things that appear to be cultural barriers to good health behavior but that can be turned into cultural assets (Bailey, Erwin, & Belin, 2000). For example, peer-perpetuated myths about diseases and disease prevention may be an obstacle to individuals adopting healthful behaviors. However, the importance placed on personal testimonies and relationships that allowed the myth to flourish can be an asset if peer educators are trained to raise community awareness about the health condition.

It is important to note the obvious fact that the self-classification term “African American” represents a range of education levels, incomes, religions, beliefs and histories. Cultural sensitivity is not to be confused with stereotypes. Instead, researchers acknowledge that shared experiences and histories may be more unique within groups of African-American women than between African-American women and women of another race or ethnicity (Guidry, Matthews-Juarez, & Copeland, 2003).

In their review of printed cancer education materials, Guidry, Fagan and Walker (1998) found that 45% of breast cancer materials for African Americans were not culturally sensitive. In the researchers' words,

Many materials included pictures of African Americans on the exterior, but failed to address African Americans either visually or verbally. Messages were placed in pamphlets that are not relevant to African Americans. This also may cause the reader to lose interest in the topic. Similarly, many printed materials did not include pictures, and researchers should be aware that African Americans are a visual culture. In addition, the format of the materials was less than conducive to the visual culture (p. 168).

Some of the approaches developers of culturally sensitive cancer prevention materials should use include addressing cancer stigma and fatalism (Bailey, Erwin, & Belin, 2000), providing risk information tailored to the audience, describing alternative and complementary treatments (Friedman & Hoffman-Goetz, 2006), and managing myths about how people get cancer (Guidry, Matthews-Juarez, & Copeland, 2003). Other issues that may act as barriers to people of that racial or ethnic group seeking health services, such as distrust of the medical system, should also be considered (Guidry, Matthews-Juarez, & Copeland, 2003). Friedman and Hoffman-Goetz suggest that cancer material should be assessed for cultural sensitivity based on whether or not the racial or ethnic group is mentioned in the content and described as the target audience for that information; if risk perceptions and alternatives to traditional medical treatment are mentioned; if the information is written in a way that the audience can understand it; if cues to the desired action are included in the content; if the producing organization's contact listed on the materials is of the same racial or ethnic group; and if the sources for the message would be trusted by readers or audience members (Friedman & Hoffman-Goetz, 2006, p. 442-443).

The Internet & Technology

For all the advantages offered by the Internet as a form of communication, its very nature results in some challenges for researchers and content providers. In fact, for every desirable

feature of Internet use, one might identify a potential difficulty for those individuals who study the technology. For instance, anonymity may be an attractive feature for Web users wishing to find out about a sensitive subject like a personal health condition; however, content developers might benefit from having basic information about the people who use their sites. Information seekers may like the fact that they can follow hyperlinks from site to site, thus locating information that specifically pertains to their interests. On the other hand, researchers know that this vast information opportunity for users severely complicates researchers' abilities to summarize or measure information seekers' online experiences.

Street and Rimal describe the Internet as having two characteristics: interactivity and modular components.⁷ The latter term refers to the ability of a technological program to link many sources of information, thus creating a non-linear information experience; the former term refers to the user control and responsiveness provided to users (1997, pp. 2-3). Taken together in the context of an online search for health information, these characteristics produce an online experience wherein a user can control what content she finds by making keystroke and mouse click decisions while the online program responds by producing a result based on those choices. As she navigates through Web pages, typically she will have many additional choices on each site – opportunities to select links to pages with more and different information. By offering numerous links on every page and not forcing a user to pick a particular link, the Web site extends more control over the content selection to the user. It also requires of the Internet user

⁷ A detailed account of the Internet's history and mechanisms is not necessary for reading this paper. Although the term encapsulates many data sharing forms, including e-mail and the World Wide Web, its use in this study refers more generally to the act of using a network-connected computer or other device to find information about breast cancer through whatever online mechanism desired.

more personal processing of the messages. Street and Rimal (1997) explain how this relates to health information-seeking and processing by saying that

...effectiveness of health promotion interventions depends, in large part, on how users process health messages...and whether this experience produced the desired results. How message processing unfolds will depend on the interaction of user, media, and message characteristics (p. 14).

Compared to a print, radio and television user, the Internet user has more opportunities to construct a unique collection of information based on her selections. She employs her mental faculties, personal and cultural preferences, and computer skills to gather a subset of Internet information and applies those same elements to interpreting what she finds.

This is an overview of why the very features that attract users to new media may hinder researchers' efforts to explore the phenomenon in a robust manner. As with all mass media studies, those that examine Internet communication either apply scientific rigor to focus on a very small aspect of use or they attempt to synthesize the experience, often placing it within the parameters of the larger social and cultural trends. On its face this study does neither. The expected outcome of the study is not a list of answers to tested hypotheses, nor is it a grand theory about the use of and effect of the Internet in people's lives. Rather the anticipated end to the project is, instead, a merger of both perspectives. It takes the knowledge already gained through other researchers' studies of the subject of Web use for health information and synthesizes it with research on African-American women's perspectives on breast cancer prevention. However, before those specifics are presented, a discussion of what the Internet is and how researchers conceptualize it as a form of communication is necessary.

The Internet is more than the sum of its parts. Many of the things the Internet allows users to do – send messages to friends, research health topics, buy products – are activities people have done for a very long time. However, the Internet offers a different way to do these things, and the

fact that these activities can be done in a different manner may change the effect of the activities. For example, a person may maintain larger connections of acquaintances with people in different geographic regions than she would without the Internet because e-mail, Internet phone, social networking, and other interpersonal communication technologies facilitate exchanges more easily than postal service mail and long distance telephone call coordination across time zones. A person who might not have been inclined to research a health topic in a public library a few decades ago might find that the convenience of fast access, home Internet service and the wealth of resources on the Web removed some or all of his barriers to health information-seeking.

Some of the features that make the Internet a useful health information tool are user anonymity, extensive and varied information, accessibility from across the world, the mix of media (such as text, audio, and video) offered, and interactivity. The first four characteristics are commonly understood, straightforward concepts, but interactivity is more complicated. One oft-cited definition of interactivity is “the extent to which users can participate in modifying the form and content of a mediated environment in real time” (Steuer, 1992, p. 84). This definition implies that the user’s action – whether keystrokes, mouse clicks, or other decisions – gives the system input and the system responds, without delay, by presenting information based on that input. In other words, both parties in the interaction receive feedback from the information exchange (Street & Rimal, 1997). Each person’s Internet experience will be different because the experience is based on the system’s available offerings and what the person seeks from it. The degree of interactivity in any given Internet tool, including individual Web sites, varies according to how responsive the source is to the user’s prompts and how much control the user actually has in shaping the content that results from his commands or selections (Street & Rimal, 1997).

Stout, Villegas and Kim (2001) suggested that interactivity is composed of many dimensions, including content and physical accessibility; multimedia forms of message delivery; navigation; data entry and user personalization; linkages between individuals; and time required to use the Internet, among other dimensions that are less relevant to this study. Advantages for health information seekers are that the Internet content can be accessed virtually at any time (Rimal & Flora, 1997); in addition, it offers social support options for people with diseases and health issues, provides opportunities for interaction with physicians and other health professionals (Street & Rimal, 1997), and the potential for messages to be tailored to meet the user's preferences (Rimal & Flora, 1997).

These Internet features may hold importance for health behavior change and health promotion. The features allow for active user involvement in interactive media that offer opportunities for individuals to learn vicariously (Jaffe, 1997) and to practice or model skills (Stout, Villegas, & Kim, 2001). When the user successfully accomplishes his or her task, be it answering quiz questions correctly or finding information that meets his or her needs (Rimal & Flora, 1997), these interactive activity successes may lead to greater self-efficacy for the user to do the promoted behavior in real life (Street & Rimal, 1997). The converse also may be true; the inability to navigate the Internet may result in reduced self-efficacy (Jaffe, 1997).

New Media Communication Theories

Theories about the roles of message deliverers and receivers have changed as both the media and the field of communication scholarship have progressed, moving from a view that the media have very powerful and direct effects on message recipients to one in which receiver processes are integrated more fully into the effects equation (Severin & Tankard, 2001). As media channels increase and new types are added, existing theories of communication and interaction with media must be tested, expanded, and have their utilities and application

parameters defined. Newhagen and Bucy (2004) offer one model for understanding the myriad variables that impact Internet use and message-receiver communication in new media. Before their ideas are presented, core concepts must be described.

In support of their belief that new media require scholars to reexamine theories of the communication process, Newhagen and Bucy (2004) define several keywords that help conceptualize the players and roles in the Internet phenomenon (Also see Bucy, 2004). First, they contend that information consists of data that are organized to have meaning that have been derived “through the use of an abstract symbol system such as language; access to that information is contingent on an understanding of that language” (p. 17). The word “organized” is important to their point because they imply a difference between random or haphazard pieces of sense data and content. The latter is a collection of “words and images structured into narrative units called content” (Newhagen & Bucy, 2004, p. 5). These narratives may be constructed and influenced through various avenues, including personal cognitive abilities and social and cultural inputs. The fact that narrative creation is not formulaic leads to the inevitability that slightly different versions of a narrative may exist.

Content’s purpose is to convey meaning to an audience, yet the variables that allow people to understand and interpret that meaning also may determine whether or not they have access to the content in the first place and whether or not they attend to the content messages. Newhagen and Bucy (2004) suggest that access is a multidimensional concept that exists on personal, social and system levels. First, there is physical access to technology that might be explained in terms of certain people possessing a personal computer with an Internet connection (or having a place where they can use a computer). Some determinants of physical access to the Internet include income and education level, which are confounding variables with race and ethnicity in the United

States at the time of this writing (Brodie, et al., 2000).⁸ Many efforts have been made to increase physical access to computers and the Internet among people identified as being “have nots” in the Digital Divide that separates the digital rich from the digital poor. Based on Bucy and Newhagen’s thoughts, one can see how physical access is both a personal access barrier and an aggregate access barrier when multiple people within some segment of the population face the same barrier.

Second, there is potential for differential content access on the personal cognitive level because the words, texts, and sounds must be decoded and interpreted using real neurological processes and skills that vary among individuals. There are also content access differences at a social level, wherein social communities place varying levels of importance on being online as opposed to other activities. The latter suggests that one’s social environment helps form a person’s schema, and that schema helps him process and interpret content.

If these contentions possess truth, the tenets, to some extent, would be observed in communication in the era before the Internet. As in the case with print and other electronic media, communicators could not exercise total control over how receivers decoded and interpreted the meanings in information they read or observed. However, the Internet is different because content creation is not centralized and produced by a limited number of newspapers or radio or television stations owned by media conglomerates acting as information gatekeepers. Through the use of Weblogs, social networking sites, and other emerging platforms for digital conversations, alternative narratives can be introduced into the communication landscape. A person’s prior schema may determine whether or not she chooses to use the Internet at all and what information she chooses to attend to online. The nonlinear nature of the Web may result in

⁸ The income variable is not found to be significant in all studies (e.g. Kind et al., 2005).

Person A having a completely different Internet information vignette than Person B because the two chose to use the technology in different ways.

These concepts intersect with the present project by suggesting that getting a Web user to attend to a certain message is a complicated effort that includes understanding the system, social, and personal level characteristics that may affect her decisions to 1) use the Internet for information about breast cancer, and 2) consider the Web page information consistent with her own constructed narrative. The ideas will be explored in the next chapter by identifying who presently uses the Internet to find health information and how and why they seek such information. Various concepts related to the factors that shape views on what constitutes a patient's role in health management as well as her identification of good health information sources also will be discussed. It is hoped that this review later will be used by others to identify a version of health information tailoring/targeting – which has been explored in other media (e.g. Kreuter & Wray, 2003; Kreuter, Skinner, et al., 2004; Noar, Benac, & Harris, 2007; Paisley & Skrzypczyk, 2005; Strolla, Gans, & Risica, 2006) – that specifically meets the needs of African-American women using the Web for information about primary and secondary prevention of breast cancer.

One of the reasons this perspective of an expanded diversity of inputs into narrative construction is interesting is how it largely mirrors the variables public health scholars believe affect a person and, by extension, the aggregate public's health. It is theorized that a person's health is a product of individual level factors such as genetics and health behaviors, social and interpersonal level variables that include cultural views of health, and system level constructs like history, racism, and politics (Kaplan, Everson, & Lynch, 2000). This multilevel determinant model of health also allows for psychological factors to exert impact on personal health. For

example, studies of how individuals perceive racism are distinctly different concepts than identified systemic racism, based on measurement strategies; however they are clearly related. A racial minority person's health may be negatively affected by his or her perception of being discriminated against (Williams, Neighbors, & Jackson, 2003), so whether or not actual discrimination occurred is of secondary importance. This example is pertinent because it is a nonphysical variable that results from narratives people and groups create and it culminates in physical effects on health. The literature is replete with studies documenting that some African Americans' existing distrust of the health care system is based on historical racism and medical experimentation. That is to say, the lens through which some subgroups in the population see health and health care seems to be a product of a narrative based both in fact and in perception. In such a case, whether or not actual racism exists in the individual's dealings with health care practitioners may be secondary in importance to the individual's perception that it exists.

At first glance this may seem entirely different from the Internet use narrative, but in essence, both suggest that the effects of culture and history on the formation of a person's narrative about health and/or the Internet as a source of health information may be as important as education, income level, and age are as use indicators. These may be critically overlooked areas of scholarship.

Street and Manning (1997) proposed a similar model to the one examined here:

...the effectiveness of health messages designed to inform or persuade is contingent on the juxtaposition of two contexts of experience. One is the mediated information environment within which the message is presented. The other is the health behavior environment that consists of other social, cultural, and economic factors that also will influence health behaviors and outcomes of interests. (p. 122).

Numerous studies and online interventions have explored evolving options for communicating cancer information to the public. These add a great deal to the body of knowledge about online health promotion but do not always adequately explain within a single

project the idea explored herein, namely how the intention and act of looking online for breast cancer prevention information is influenced by both health beliefs (about breast cancer) and beliefs about the Internet as a tool for accessing such information. Intuitively we can expect individual, social and cultural, and macro factors to influence women's schemas or meanings about breast cancer and about the Internet; however, this study is designed to explore the intersection of those meanings in order ultimately to hypothesize about whether or not women without cancer diagnoses would or would not utilize online information about breast cancer primary and secondary prevention. If it can be determined that their beliefs about, and meanings of breast cancer influence their decisions not to seek information, then the point of intervening to increase their information-seeking behavior would be different than the strategy for increasing searches in women who describe technology barriers (physical access, distrust of the medium, Internet skills, etc.) as their hindrance.

This study did not answer this important abstract question, but the approaches employed provided good initial insight into the meanings women make of primary breast cancer prevention and the use of the Internet for information about the topic. It should allow researchers to probe the raised questions using other measures to determine how well the themes discovered in the study represent African-American women's beliefs, as well as to employ additional qualitative methods to explore the topic in more depth.

The study specifically focused on African-American women because they represent an identifiable population subgroup about which there is research that reveals certain cultural views about health behavior and technology use as well as unique breast cancer patterns. Also, the African-American population has lower income and education than white Americans, thus limiting their health resources. Gustafson, et al., partnering with the National Cancer Institute's

Extraordinary Opportunity in Cancer Communications program, suggested that a mechanism for reducing cancer disparities is “increasing the knowledge about, tools for, access to, and use of cancer communications by diverse populations” (2005, p. 174). Understanding how to design, implement, and disseminate materials that are tailored to diverse populations’ needs is vital to this goal.

The study is not based on assumptions of consistency among African-American women’s health and Internet behaviors and personal beliefs about these things; however, it does utilize the extensive literature that tells us something about the social and cultural influences on health and technology use.⁹ Within this proposal are reviews of the literature about breast cancer in women and specifically in African-American women, Internet use by African Americans and other Americans, online health information-seeking by the general public and by those with breast cancer, and how these may or may not support the idea that the act and process of looking online for breast cancer prevention information may be affected by beliefs about breast cancer as well as beliefs about the Internet.

⁹ Another important note is that men can and do develop breast cancer, but because the rates are much lower than those in women, this study focused only on women. Logically, men’s perceived risks of breast cancer and their intention to look for information also should be lower and that is why including men in this study would be inappropriate to the study’s aims.

CHAPTER 2 LITERATURE REVIEW

The Breast Cancer Experience in African-American Women

African-American women have lower rates of breast cancer diagnoses than white females, but they are more likely to die from the disease (ACS, 2007b). There are numerous theories about why this is the case. Like most ecological health models, these theories exist at the personal level in the form of such factors as genetic differences in breast cancer types (Amend, Hicks, & Ambrosone, 2006), social and cultural levels including different culturally-held views of health, breast cancer and prevention (Lannin, et al., 1998), and at the system level in terms of access to health care and racism or perceived racism within the medical community (Williams, Abbott, & Taylor, 1997).

Some scientists suggest that a different, more aggressive variant of the disease may be present disproportionately among African-American women (Amend, Hicks, & Ambrosone, 2006). One curious piece of evidence that may support a biological explanation is the fact that breast cancer is diagnosed more often in much younger black women than among younger white women. Another proposed reason for the discrepancy is that tumors are found at a more progressed stage in African-American women. This hypothesis can be interpreted in several ways. It might mean that by the time the disease is discovered in a black woman, it has progressed further than is the case for the average white woman with breast cancer. It can also be interpreted that there's a longer delay between diagnosis and treatment for African-American women (Gorin, Heck, Chang, & Smith, 2006). The distinction may be small, but it is important to discuss because it may identify any system-level problems that prevent early detection and/or treatment of breast cancer in African-American women.

Mammograms, the tests included in both the American Cancer Society and National Cancer Institute's guidelines for breast cancer screenings in women older than 40, are administered as a form of secondary prevention for breast cancer. The goal of mammography in breast cancer control is to detect tumors at their earliest, most treatable stage, thus preventing death from the disease and spread to other parts of the body. There have been conflicting findings about the rates of mammography screenings in African-American women, possibly reflecting fluctuating rates per year. Tessaro, Eng and Smith (1994) found lower utilization of mammography in black women compared to white women, but in a later study, Jones and colleagues (2003) found no significant difference in screening rates by race. Recently, Williams, Lindquist, and colleagues (2008) found an association between lower income and less screening in older women. Although that study did not focus on race, the findings raised questions about the connection between money (of which African Americans, on average, have less than white peers) and screening behaviors.

Access to healthcare is another factor that may influence breast cancer prevention (Wolff, et al., 2003), diagnoses, and outcomes in African Americans. Private health insurance rates for black citizens are lower than for white Americans. They are more likely than their white peers not to have a regular care doctor and more likely to utilize emergency rooms and county health departments for health services. Even though many of these differences disappear when controlling for income and similar socioeconomic factors, suggesting that the relationship may be a result of financial circumstances and not race, it remains that such negative socioeconomic factors disproportionately apply to African Americans in the United States; therefore understanding the effect of health care utilization is important to identifying the factors that result in health disparities.

Distrust of the medical system also may play a role in African Americans' health care decisions (Wolff, et al., 2003). A history of unethical medical practices on black people in the United States dates back hundreds of years but occurred in its most concrete – and perhaps best-known – form in the Tuskegee syphilis experiments. Beginning in 1932, the U.S. Public Health Service agency withheld information about known treatments for syphilis from a group of male farmers in Tuskegee, Alabama, in order to learn more about the natural progression of the disease (Centers for Disease Control, 2008). As a result, the men enrolled in the study and their families suffered unnecessarily from the illness's effects. Although formal recognition of this unethical practice has since been made, and some financial restitution to the families was provided, the incident is often cited in research on African Americans' perspectives on the medical system as a reason for distrust. Also, use of culturally insensitive or ineffective prevention strategies targeting African-American communities may have a non-optimal effect on health (Wolff, et al., 2003). Kreps (2006) suggested that prevention information campaigns should take into account the trusted communication channels and interpersonal networks for the targeted health messages.

Poverty as an overarching and related factor may play a major role in the burden of breast cancer disease in African-American women. Slightly more than 23% of this racial minority lived in poverty in 2006, compared to about 10% of white Americans (DeNavas-Walt, Proctor, & Smith, 2007). Poverty has been associated with many negative health indicators (LaVeist, 2005).

Moving backward from screening and mortality to primary prevention, it has been suggested that a large percentage of cancers are preventable through behavior modification (Institute of Medicine, 2003). Tobacco use, low levels of physical activity and obesity are three behavioral components believed to increase breast cancer risk. While no agencies have produced

estimates of how many breast cancer diagnoses might be prevented if the obesity problem in African Americans was assuaged, recent research has yielded some evidence that excessive overweight may be negatively associated with breast cancer survival (Hede, 2008). Estimates are that as many as 80% of adult female African Americans are overweight or obese (Minority Women's Health, 2007).

Phillips and Williams-Brown (2005) suggest that community resources necessary to sustain behavior change in areas like tobacco use are lacking in ethnic minority communities. Similarly, these communities may lack the social capital to examine links between environmental conditions and disease development.

Health Beliefs and Beliefs about Breast Cancer in African-American Culture

Views of breast cancer and general health perspectives in some African-American cultures may present challenges for public health experts working with communities to encourage prevention. The same idea of distinct cultural views of health issues would be found in many other subcultures, be they categorized by race/ethnicity, age, or lifestyle groups. However, this paper is concerned with the culture-specific qualities identified in the literature as possibly interfering with healthful breast cancer prevention behaviors.

Studies have found that breast cancer was (and may still be) perceived as a private topic among African Americans, such that mothers often did not share experiences or information about the disease with their daughters (Matthews, et al., 2002; Moy, et al., 2006). In communities where this is the case, women may not talk openly about the risks of breast cancer or encourage information-seeking. In families that have experienced breast cancer first hand, the situation may actually have the effect of discouraging information-seeking about the disease. Matthews, et al., (2002) suggested that "...a family history of cancer was also cited as a major emotional barrier to cancer information seeking and active involvement in treatment" (p. 212) because cancers in

African Americans are often found at late stages, when treatments are more invasive and survival rates are lower.

Conflicting reports about African-American women's perception of risk have come from the literature. Some have found that perceived risk of cancer is lower in African Americans than among white women (Honda & Neugut, 2004; Haas, et al., 2005). Another study revealed that African-American women had lower perceptions of mammography benefits than white women but that the black participants' perceptions about mammograms' efficacy was actually more realistic than the white participants' reports (Haggstrom & Schapira, 2006). In other words, white women overestimated the efficacy of mammography screenings while the black women's estimates were more accurate.

Myths about breast cancer and treatment may prevent some women from seeking treatment. One major issue is the belief that breast cancer is a death sentence, which may result from the high mortality rates in African-American breast cancer patients (Moy, et al, 2006). For example, Haggstrom and Schapira found that black women were more pessimistic about their survival chances compared to white women, but "a greater proportion of black women accurately perceived breast cancer survival than white women" (2006, p. 373). In other words, black women are more likely than white women to believe they will die if they get breast cancer, and based on the mortality rates previously cited, there may be ecological support (as opposed to individual case prognoses) for that pessimism. And Matthews, et al., (2002) found that fear about deaths from a cancer diagnosis might prevent African-American breast cancer patients from seeking health information and from complying with their recommended treatments following a cancer diagnosis, if they do not think cancer is survivable. Another belief that may be prevalent in some African-American communities is that cancer is spread by cutting into it (Matthews, et

al., 2002) and that breast cancer is related to breast trauma, which is sometimes caused by domestic physical abuse. Simon found that some women might not be screened for breast cancer due to the fear that it “could result in unwanted revelation of the abuse” (2006, p. 39). Although one recent study by Retsky and colleagues (2007) suggested a possible link between surgery for some tumors and increased mortality, according to the National Cancer Institute (2005a), there is no scientific support for this association and it remains a cancer myth.

Trust issues also play a role in breast cancer health decisions. Mistrust of medical doctors (Matthews, et al., 2002) as well as the medical test technologies (Powell, et al., 2005) and the previously mentioned pessimism about mammography benefits compared to white peers (Haggstrom & Schapira, 2006) have been suggested as reasons why African-American women may not adopt preventive and screening behaviors. For this reason, Moy et al. (2006) emphasize the importance of good relationships between primary care physicians and staffs and their patients, and Glanz and colleagues (2003) raise the point that understanding the communication differences between providers’ cultures and those of the patients is vital.

Another way trust plays a role in health beliefs and behaviors is in the area of faith and religion. The church is an important part of many African-American communities. While researchers point out the complexity of the relationship between religion and personal health perspectives (Bowie, Curbow, et al., 2001), it remains that the theme of God being in control of one’s health and life may affect attitudes and beliefs about breast cancer screenings and treatments. Simon found evidence that participants believed “only God can cure cancer and thus they questioned the purpose of breast cancer screening” (2006, p. 39). A participant in Matthews and colleague’s qualitative study said, “They say that ‘God is going to take care of me, he is

going to cure me,’ and there is [such] a spiritual belief in some individuals that they don’t take the extra step [to care for] themselves” (2002, p. 213).

Some of the other barriers to breast cancer prevention behaviors are logistical in nature. African Americans often face many competing health issues, such as social problems in their communities, so that breast cancer prevention may be perceived as less of a priority (Wolff, et al., 2003). Similarly, the prevalence of other diseases like HIV in the community may be considered more pressing needs (Moy, et al, 2006). Lack of time for mammography screenings has been identified as a barrier (Powell, et al., 2005), as has the fear of losing one’s hair due to chemotherapy if a tumor is found and treated (Simon, 2006).

One study that examined African-American breast cancer patients’ and survivors’ barriers to losing weight (a positive health behavior change thought to prevent recurrence) found that the women wanted to adopt more healthful eating and exercise habits but faced barriers similar to those faced by the general public, as well as some specific to their cultures (Stolley, et al., 2006). For example, women cited having too many nutrition recommendations by experts, not liking the taste of healthy foods, and finding it difficult to prepare a dish just for themselves as factors that negatively impacted their dietary change perceptions. A culture-specific (be it a racial/ ethnic or Western culture commonality) finding was that food served as a “centerpiece of family occasions” (p. 619).

All of the barriers mentioned so far relate to personal or social health beliefs and behaviors, but not all public health advocates accept the idea that changing health behavior is an effective way of decreasing health problems in disadvantaged populations (Marks, et al., 2006). In other words, changing behavior may only do so much if the people face obstacles like environmental, education or economic hardships. Low income and low education African-American women

have a 50% higher risk of being diagnosed with advanced stage breast cancer than more educated women with higher incomes (Gustafson, et al., 2005, p. 174). And Consedine and colleagues found that, “(i)n many cases, race and income have independent or additive predictive value in terms of cancer and screening behaviors” (2007, p. 551).

Health Literacy

Federal health care officials have referred to public health literacy as a major challenge facing the nation, suggesting that reducing the country’s health disparities depends on increasing health literacy (Carmona, 2006; United States Department of Health, 2000). According to a 2003 survey by NALS, 75 million American adults score in the basic and below basic health literacy categories (Kutner, 2006), with the highest number of low literates being U.S.-born white citizens, but higher in-group percentages being found in minorities (Sentell & Halpin, 2006), the elderly, the poor, the homeless, prisoners, and military recruits (Weiss, 2005).

In addition to reading skills, people need other skills to understand health issues and make choices about their personal health – to be health literate. Health literacy is a multidimensional measurement of abilities to function in a health care environment. Healthy People 2010 defines health literacy as, "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (United States Department of Health, n.d.). It has also been defined as the skills and abilities used to navigate through health messages, information, and the health system (Bernhardt, Brownfield, & Parker, 2005). Although health literacy is related to people’s basic reading and numeracy abilities (Ad Hoc, 1999) and education level is highly correlated, it is not always predictive of health literacy (Conlin & Schumann, 2002). Health literacy goes beyond recognition of words and numbers; health literate people also understand this information, are able to use it to make good decisions about their health (Weiss, 2005), and can adapt to changes

in the continuously developing health science (Kickbusch & Ratzan, 2001) and communication technology fields with “evolving skills and competencies” (Zarcadoolas, Pleasant, & Greer, 2003, p. 119). Health literacy is context-specific—meaning that a person might possess good skills when negotiating communication with his doctor but poor skills when searching the Web for health information. People need skills and knowledge to read medical prescription bottles, complete paperwork at doctors’ offices, and search for and understand health information in the mass media (Bernhardt, Brownfield, & Parker, 2005) in order to make good health decisions for themselves and their families.

Low health literacy results in an estimated \$73 billion wasted annually due to “poor information sharing and exchange” (Zarcadoolas, et., al, 2002, p. 320; Carmona, 2003). Improving health literacy not only is good for the country’s bottom line and general health, it also serves as an empowerment tool (Zarcadoolas, et al., 2002), giving people skills to make their own health decisions. Understanding health has been linked to a more comprehensive view of health opportunities. Guerra, Dominguez and Shea found that functional health literacy was associated with awareness of colorectal cancer and tests to detect it (2005). This type of health literacy might be better classified as “health awareness” or “health knowledge” (Baker, 2006).

Although scholars regularly cite a lack of a clear definition of health literacy (Zarcadoolas, Pleasant, & Greer, 2003; Baker, 2006), it appears that health literacy is a multidimensional concept not unlike the model of Internet access and the ecological model of health described in this paper in terms of its antecedents and effects. Health literacy may require possessing fundamental/numeracy skills (such as reading, vocabulary, and math skills), science and technology literacy, and community/civic, and cultural literacy (Zarcadoolas, Pleasant, & Greer, 2003). Researchers have connected income, education, and language skills (Pawlak, 2005;

Nutbeam & Kickbusch, 2001), and even individual beliefs and attitudes with health literacy, although the association between functional health literacy and beliefs and attitudes is inconclusive (Guerra, Dominguez, & Shea, 2005).

As an example of health literacy scholarship, a large body of literature focuses on how patients' health literacy levels correspond with their understanding of medical directions and prescription labeling (e.g. Conlin & Schumann, 2002; Ross, Potter & Armstrong, 2004; Davis, Wolf, Bass, et al., 2006), with implications that patients' adherence to medical practitioners' advice may be linked to the ability to read the instructions (Wolf, Bennett, et al., 2005). Another line of health literacy research involves assessing the public's understanding of health and science, which studies indicate is low among the United States population (Payne & Schulte, 2003). Health literacy researchers in the communications field also study the readability of health information produced for patients and the general public (e.g. Daghighi, Fattori, & Ciardullo, 2006). Overall, there is evidence of a gap between the levels at which health materials are written and the reading levels of the general public (Rutherford, Holman, et al., 2006). And a fourth – that which is most relevant to this study – is the area of research focused on health information provision and information-seeking behavior on the Internet (e.g. John, 2005; Bremner, et al., 2006; Hong, 2006). Included in this category are findings that Internet sites for breast cancer may be written at 11th- to 12th-grade and college reading levels (Friedman, Hoffman-Goetz, & Arocha, 2006), much higher than the level at which the NALS study indicates many Americans read, and that the average online health information consumer may not be able to distinguish between high and low quality information (Bates, Romina, Ahmed, & Hopson, 2006). These findings are significant to cancer communication because low health literacy contributes to

individuals' difficulties understanding cancer information, their knowledge of screening tests, and their beliefs about cancer prevention (Davis, Williams, Marin, Parker, & Glass, 2002).

A major tenet of health literacy understanding is that it is contextual, meaning that a person with high health literacy in one area (e.g. understanding television news stories about a health issue) may have low health literacy in another situation (e.g. finding good sources of health information on the Web). The gap between the levels at which health materials are written and the reading levels of the general public parallels the gap in computer skills. When older, poorer, and less educated women use the Internet, people in these subgroups have a harder time locating the information they need quickly, most likely due to a lack of familiarity with the technology (Hargittai, 2002).

Digital divide issues continue to concern communication researchers studying e-health information. Although the Pew study suggests that Internet use has diffused through much of America, there are still questions about who has access to the technology (Fox, 2006; Baur, 2005). Beyond access, there are major barriers to the Internet's use. Specialized technical skills are required to browse the Web using toolbars, links, pop-ups and radio buttons. The highly textual Web platform presents difficulties for people with low reading and comprehension skills. These may be insurmountable obstacles for people with visual, mental and some movement disabilities.

A final issue related to health literacy on the Web is information-seeking skills. Research into the search strategies employed, page selection, and decision making by users is ongoing. Still, Baur (2005) suggested that the use of the Internet in health information provision may be too new to understand its part in the health literacy problem.

Ecological Studies of Information-Seeking

Large scale surveys have yielded very useful insights into the scope and trends of Internet access and health information-seeking. The Pew Internet & American Life Project regularly conducts surveys to determine what segments of the country's population are using the Internet, for what purposes they use it, and by what means they access the Web. Similarly, the Health Information National Trends Survey (HINTS) is administered by the National Cancer Institute and produces extensive data useful to many studies of health communication.

Based on these data sources, we know that use of the Internet for health information increased from 2003 to 2005 (Rutten, et al., 2007). Eighty percent of Americans with Internet access have searched for health information online, with most of them looking for information about diseases and medical problems (Fox, 2006). Rates of Internet health information-seeking vary by age but are relatively high across groups, ranging from a low of 68% among users older than age 65 to 84% among 30- to 49-year-olds (Fox, 2006). Women search for health information on the Internet at a slightly higher rate (82%) than do men (77%); however a significant portion of both sexes engage the medium for this purpose (Fox, 2006). Health information seekers on the Web do not only look for information for themselves. Almost an equal number of users searched for personal medical information (58.4%) as said they sought this type of information for someone they knew (59.5%) (Rutten, et al., 2007, p. 16).

The Internet as a health information source is gradually diffusing across demographic groups, but some personal characteristics have been associated with higher rates of online health information-seeking. For example, health status is associated with use, as people in poor health are more likely to seek information than healthy people (Houston & Allison, 2002). Individuals with chronic illnesses are among the highest users of the technology for this health

information-seeking purpose, though other factors such as health insurance status, education, and age, to some extent, affect the usage rates (Bundorf, Wagner, Singer, & Baker, 2006; Helft, Eckles, Johnson-Calley, & Daugherty, 2005). Women are more likely to use the Internet for health information than men (Fox, 2006), but older, low income, and low education women use it at lower rates than other women (Mancini, et al., 2006; Ramanadhan & Viswanath, 2006; Hall, Dunkelberger, & Wheat, 2005).

Health information on the Internet is a much studied topic. While the Internet is a broad medium that encompasses interpersonal activities such as e-mailing, message board postings, and other forms of two-way communication, the World Wide Web component dealing strictly with the provision of health information on Web sites has received a great deal of scholarly attention. Four frequently studied areas are health information-seeking as a process activity (e.g. Bader & Theofanos, 2003; Morahan-Martin, 2003; Coiera & Vickland, 2008), the quality of health information on Web sites (e.g. Meric, et al., 2002; Schmidt & Ernst, 2004; Walsh-Childers & Edwards, 2007), the reading level and amount of health literacy required to comprehend Web page information (e.g. Kaphingst, Zafini, & Emmons, 2006; Friedman, Hoffman-Goetz, & Arocha, 2006; Berland, et al., 2001), and the effect of finding online health information on disease treatment and health maintenance (e.g. Silence, Briggs, Harris, & Fishwick, 2007; Powell, Low, Griffiths, & Thorogood, 2005).

The Internet's democratic nature allows anyone the opportunity to develop his or her own Web site devoted to a disease like breast cancer. Quality and accuracy of this information is mostly unverified and not subject to a set of medical standards. Physicians report some concerns that their patients are not accessing good, evidence-based health sources on the Web. They also

express worry that patients with low literacy skills and those who speak Spanish are not able to find credible information (Perocchia, Rapkin, et al., 2005).

Poor quality or inaccuracy in health information Web sites is one area of communication researchers' concern (Eysenbach, Powell, Kuss, & Sa, 2002). People's reliance on generic information search engines such as Google that use link popularity to generate page recommendations may result in their selection of misleading or medically inaccurate sites. For example, Ekman and colleagues (2005) found that sites offering cancer gene test services very commonly included fearful messages that one's family history might make individuals more susceptible to cancer. They concluded that instead of providing good prevention advice, "(t)he abundance of these family history questionnaires could give a skewed idea of the major cancer risk factors and the magnitude of the risk they convey irrespective of the type of cancer studied" (2005, p. 771). Christensen and Griffiths (2000) found that depression Web sites included information that was of poor quality and inconsistent with the consensus among the mainstream medical community. A recent analysis of popular breast cancer Web sites found that the type of information provided on them was very different from the information breast cancer experts thought patients should know about the disease (Walsh-Childers & Edwards, 2007).

Source credibility is a major concern for researchers. Previous research has suggested some criteria people use to determine the quality of health information. The inclusion of authoritative sources, scientific references on the page, and a professional look to the site are a few elements researchers cite (Eysenbauch & Koher, 2002). Factors like people's knowledge, in addition to their perception of a Web site's trustworthiness, source expertise, and depth have been found to influence whether or not the Internet users return to that site in the future (Hong, 2006). However, in experiments, participants looking at health Web sites did not pay enough

attention to the authority or source of the information to recall it when prompted later (Eysenbauch & Koher, 2002). The distinction between these contradictory findings is that people cite one set of criteria, but experiments suggest that the reality may be different. When considered together, these findings raise the question of whether or not people are influenced by bad health information both in the short term and long term by not fully evaluating a Web site's authority. If people use trustworthiness as a reason to return to a site, it is important that they associate trustworthiness with credible sources like the Web sites of the National Cancer Institute or the American Cancer Society. Research suggests that this association is not happening because people may not consider the Web site author and other factors, such as references to scientifically accepted sources of information about cancer, when they select a health information Web site (Bates, Romina, Ahmed, & Hopson, 2006).

It is possible that people may choose Web sites because the material is presented in a certain appealing way. Personal stories by individuals who have experienced cancer may be more desirable to seekers than comprehensive and scientific sites that are harder to understand (Wathen & Harris, 2007). Due to the current state of Web information and the possibility of finding incorrect advice, it is important to improve users' Web skills (Hall, Dunkelberger, & Wheat, 2005).

There is a disconnect between where people want to get cancer information and from which source they actually seek it, as demonstrated by the fact that close to half (47.6%) of HINTS respondents said they had turned to the Internet the last time they needed cancer information compared to the 23.5% who had asked their health care providers (Rutten, et al., 2007, p. 28-30). While most Americans favored their personal health care provider (55%) as the source of cancer information, nearly 28% cited the Internet as their preferred source, a slight

decrease from when the same question was asked in 2003 (Rutten, et al., 2007, p. 19-20). The order of source preferences was the same for white and black Americans, even though the percentages differed some. A recent survey suggests that people are unlikely to talk to their doctors about what they learn from Internet health sites (Fox, 2006). This is important because more than half of Internet health information seekers report that what they find affects their disease treatment decisions (Fox, 2006).

Breast Cancer Information-Seeking

Women account for more than half of Internet cancer information seekers (Rutten, et al., 2007, p. 25). Search rates for cancer information vary across age and ethnic groups, ranging from 42% to 55% in women aged 18 through 79 years (Rutten, et al., 2007, p. 25). People identifying themselves as Hispanic use the Internet for cancer information at a much lower rate (25%) than members of other race and ethnicity groups. Approximately 47% of black Americans use the medium for this type of information, and almost 55% of white Americans are online cancer information seekers. Education attainment is positively associated with rates of Internet cancer information-seeking, as is household income (Rutten, et al., 2007).

It is difficult to estimate how many breast cancer patients use the Web to find information or services related to their disease. A meta-analysis suggests that about 39% of cancer patients do so (Ramanadhan & Viswanath, 2006). However, isolated studies suggest that it is used by anywhere between 10% and 43% of breast cancer patients (Satterlund, McCaul, & Sandgren, 2003; unpublished data cited in Weissenberger, et al., 2004). Also hard to determine are specific usage differences among demographic groups of women. Similar to overall Internet trends, breast cancer patients who use the Internet for health information are generally younger, better educated, and have higher incomes than non-users (Fogel, Albert, Schnabel, F., et al., 2002).

Minority women with breast cancer use the Internet to find information about their disease at very low rates (Talosig-Garcia & Davis, 2005).

Access to the technology is certainly an issue that influences use. When that barrier is removed, such as when Gustafson, McTavish, and fellow researchers (2005) studied women who were provided with computers as part of the Comprehensive Health Enhancement Support System program, lower income women actually used the Internet more often than affluent participants. Uses also differed by race as it more often served a communication purpose for Caucasian women, whereas African Americans used it for information.

For some women with cancer, the Internet is an important resource because of the medium's characteristics, namely on-demand access and user privacy (Gustafson, McTavish, et al., 2005; Ziebland, Chapple, et al., 2004). Christensen and Griffiths (2000) offered that the Internet's capacity to be interactive, to be accessed from across the world, to disseminate information quickly, and to provide a nearly infinite amount of information make it a natural and exciting potential tool for increasing health literacy. The Internet's appeal as a health resource cannot be denied. It is a multi-use tool that offers opportunities for patients to look for health information, to participate in online support groups and message boards dedicated to cancer issues, and to communicate via e-mails exchanged with their doctors and with friends, family members and other cancer patients and survivors. All of these activities may serve as coping mechanisms for the patients (Eysenbach, 2003). Being well informed on matters related to the disease and treatment also allows women to be active participants in their breast cancer management (Ramanadhan & Viswanath, 2006).

Women with breast cancer consider information about their disease, such as the likelihood of its recurrence after treatment and family members' risk of developing it, to be highly

important (Raupach & Hiller, 2002). Patients receive more information from their medical care providers in the early months after diagnosis and during treatment but come to rely on other sources as time passes (Raupach & Hiller, 2002). Often cancer patients have questions that are not fully answered by their doctors (Engelman, Perpich, et al., 2005).

Despite the high rates of people seeking cancer information on the Internet and from other sources, the information they find often lacks usefulness. Reported trust in the Internet as a source of health information appears to be inconsistent with rates of use, as only 18.9% of people place a lot of trust in online health information (Rutten, et al., 2007, p. 22). Arora and colleagues (2007) suggest that looking for cancer information is a frustrating experience for many Americans.

While women would like to receive answers to their breast cancer questions from their physicians, they also seek out additional sources of information (Johnson & Meischke, 1991). Health information seekers consider their personal doctors' online information to be their most trusted source, with medical universities and the government following in second and third place (Dutta-Bergman, 2003). In the mix of additional information resources, 13% of patients consulted the Internet first in a study published in 2005 (Talosig-Garcia & Davis). Patients also report consulting the Internet before talking to their medical practitioners in order to be knowledgeable about the condition (Sillence, Briggs, Harris, & Fishwick, 2007). Satisfaction with the Internet as a breast cancer information provider is quite high among women, certainly higher than their satisfaction with other media's delivery of such information (Raupach & Hiller, 2002).

Beyond looking for answers to breast cancer questions, women use the Internet to become active participants in their disease management. Ziebland and colleagues suggested that Internet

use is “transform[ing] roles and chang[ing] involvement in health care” because it allows patients to question medically prescribed treatment plans and become knowledgeable and empowered instead of merely disease victims (2004, p. 328). They found that the anonymity of online searching lets patients maintain non-confrontational relationships with their physicians while secretly checking the professionals’ advice as well as the medical facilities’ quality. Not surprisingly, patients’ use of the Internet for health information may affect the doctor-patient relationship when patients find information about alternative treatments or facts that conflict with what their doctors have told them (Bass, et al., 2006; Cerully, Klein, & McCaul, 2006). If this furthers dialogue between the medical team and patient, the result may be positive. However, it may have negative implications for patient treatment compliance (Bass, et al., 2006).

Oncologists’ opinions regarding the Internet’s impact on their patients are mixed, with most of these specialists saying that the information patients find generally raises hopes (in addition to anxiety), but offering conflicting views of whether this hope is good or not. At any rate, oncologists report that discussing information patients find on the Web has noticeably increased appointment lengths (Helft, Hlubocky, & Daugherty, 2003). More than half of cancer patients’ caregivers who search for information about the disease online say that they ask the physicians about the results during consultations (Kirschning, Kardorff, & Merai, 2007).

Women would like to receive Web site recommendations from their health care provider to help the patients avoid pages filled with complex medical jargon (Mancini, et al., 2006). It remains unclear how doctors interpret this new information source. In one study broaching the topic, more than 90% of rural West Virginian patients said their doctors never suggested any Internet source for reference (Chandra, Rutsohn, & Carlisle, 2004).

What information do they seek?

Research conducted when the Internet was gaining popularity as a source of health information found that women used the medium to search for more information about their disease than their physicians had provided, as well as information about other treatment options (Pereira, Koski, et al., 2000). Among breast cancer patients, specific information needs vary by age, as younger women are more likely to want information about the effect of treatments on childbearing and such than are older patients (Williamson, 2005). Also, the types of information breast cancer patients want changes as they move through stages of their disease experience (Leydon, Boulton, & et al., 2000), but usage remains consistent (Satterlund, McCaul, & Sandgren, 2003). Newly diagnosed patients want to know about disease prognosis, causes, risk factors, treatments, and side effects (Talosig-Garcia & Davis, 2005). The type of breast cancer information patients seek online may be different from what they get from physicians and other health professionals. Personal testimonies by cancer survivors have been found to provide new patients with information for managing their own disease (Leydon, et al., 2000).

Needs also depend on whether or not the Internet user seeks the information for herself or someone else. Research shows that rural patients seek cancer information for others, presumably friends and relatives, at high rates (Engelman, Perpich, et al., 2005). Cancer patients' loved ones report seeking information about the disease for their own knowledge first, but also to share with the patient (Kirschning, Kardorff, & Merai, 2007).

Research has suggested that women may consciously seek or avoid information about breast cancer following their diagnoses with the disease. One study found that information seekers found the action to be a way to cope with cancer, to gain a perception of control and security in the face of uncertainty, and to help them make health care decisions. The women in

the study who avoided cancer information did so because it depressed, scared or worried them (Rees & Bath, 2001). Conversely, use of the Internet by cancer patients may be an important coping strategy that is associated with improved quality of life (Owen, et al., 2005). Whether or not this Internet-coping link exists across the board for all cancer types is disputed. Fogel (2004) found that the Internet did not meet a coping need for breast cancer patients using the medium independently. He suggested that this contrast with previous scholars' findings of a coping effect for patients might be explained by the earlier studies' use of a medical librarian to help patients locate good information instead of the patients seeking the information themselves. This discrepancy raises important questions about whether the benefits of accessing a wealth of cancer information on the Web are offset by women's frustrations in attempting to locate good material and the overwhelming task of surfing through all of the available sites.

Support for cancer patients is important for coping and managing their health. However, patients who live a great distance from available support groups and programs may not be able to travel to meetings or functions that offer this benefit. Studies of Internet support group involvement have indicated that the medium does provide welcome psychological and physical coping strategies for its users (Owen, et al., 2005). It may be a useful resource for breast cancer patients even after the successful treatment of their disease (Satterlund, McCaul, & Sandgren, 2003).

Questions of how and why women use the Internet for cancer information have been explored using a variety of methods, including in-depth interviews (e.g. Leydon, et al., 2000). From them we have learned the aforementioned fact that people tend to start health searches with generic search engines. Choice of search engine varies, with some reasons being the search engine format, it appearing on people's home pages, and finding an engine useful after seeing

someone else using it (Peterson, Aslani, & Williams, 2003). Searchers spend a median of 37 seconds on a page and usually click only on links presented on the first page of search engine results (Eysenbach & Köhler, 2002, p. 575).

Although one might presume that gaining information about breast cancer would be associated with knowledge increases, this educational process is more complicated. Variables such as the way online information is presented (e.g. if it is in a two-way communication format or a straight text presentation) may lead to different learning outcomes for women accessing breast cancer information on the Internet (Shaw, Han, et al., 2007). Ability to comprehend the Web content also may affect both what women learn about breast cancer and which sites they select as sources. Research analyzing cancer Web sites' reading levels reveals that many use text consistent with upper high school and college level reading skills (Friedman, Hoffman-Goetz, & Arocha, 2004), although breast cancer sites appear to be written at a lower reading level than those devoted to other cancer types (Friedman, Hoffman-Goetz, & Arocha, 2006).

Obstacles to Use

The biggest and most obvious barrier to women's use of the Web to find breast cancer information is lack of computer access (e.g. Ziebland, Chapple, et al., 2004). An Australian study of breast cancer patients' interest in using the Web for information about the disease revealed that deficiencies in skills, lack of access to the Internet, and a lack of interest were key reasons why women did not use the Internet for this purpose. However, 41% of survey respondents indicated an interest in learning more about using the Internet to find health information, with no significant difference between rural and urban women's interest (Winefield, et al., 2003, p. 31). In response to this perspective, programs and research attempting to reduce this barrier have provided study participants with computers to examine how the women would use the technology (e.g. Shaw, et al., 2006). Those studies have shown that women provided with

computers may use them to find breast cancer information, and these women reported more self-efficacy in making decisions about their medical treatment (Gustafson, et al., 2002).

The HINTS survey asks respondents about their cancer information-seeking experiences. Rutten and colleagues' (2007) analysis of the 2003 and 2005 HINTS data found that nearly 40% of respondents said it "took a lot of effort to find," about one quarter said it "was frustrating to obtain," almost half said they were concerned about the information's quality, and over 20% said it "was too hard to understand" (p. 24). Although the rates of people reporting agreement with these statements in 2005 is high enough to cause health communicators some concern, all have dropped considerably from when the survey was administered in 2003, when almost 50% reported great effort to find information, about 40% feeling frustrated, nearly 60% expressing concerns over information quality, and almost 40% finding the information hard to understand (Rutten, et al., 2007).

Minority Use of the Internet

There have been studies aimed at defining and describing the Internet experience for racial and ethnic minority groups. Like other surveys of the Internet use landscape, many of them have gauged access to the technology in order to see if and where a "digital divide" exists. In their study of urban African Americans and Internet use for information about diabetes, Jackson and colleagues (2005) found that 46% of their participants knew how to use computers (based on self-reports), 40% owned their own computers, and the majority of people who did not have computer skills "were willing to learn" how to use the technology (p. 578).

Although home computer ownership was limited to 58% of participants in a study of urban African-American caregivers of pediatric outpatients, 93% agreed that "there is useful information about health on the Internet," and almost the same percent thought that online medical information should be discussed with a doctor. Fifty-two percent reported having

searched for health information online, and 82% of them said the information impacted their health decisions (Kind, et al., 2005, p. 118). The authors of that study put the findings in context of physician-patient communication and pointed out that doctors should not assume that minority and low income patients and their caregivers have not used or been influenced by the Internet.

Effects of Internet Use on Breast Cancer Information Seekers

While a great deal of research has investigated the use of the Internet by breast cancer patients, this likely differs substantially from the experience of someone who has not received a breast cancer diagnosis and seeks information about primary or secondary prevention of the disease. Unfortunately, extensive studies about what prompts African-American women without cancer histories to seek or avoid prevention information on the Web have not been published in the literature. Therefore much of what is known about African-American women's use of the Internet for breast cancer information comes from research with subjects identified as cancer patients or survivors. The extent to which this circumstance affects the studies' relevance to this current project is unknown, but it is a probable issue. There likely is something profound about a breast cancer diagnosis that causes women to change their information-seeking habits.

Fogel and colleagues' (2003) found that for African-American women who used the Internet during and after their breast cancer experiences, the technology provided them more perceived social support than the white women in the study reported. Minority participants in that study also saw the Internet as providing "tangible benefits of possible concrete advice or directives relating to breast cancer" (p. 114).

Summary and Research Questions

African-American women have higher rates of mortality from breast cancer than do white women. Detecting tumors at later stages reduces survival rates for breast cancer patients and, based on some evidence, black women find and/or begin treatment for their breast cancers at

later stages than white women. There are many hypothesized reasons for this disparity, and likely it is the result of many factors, some of which have been described. Promoting healthy lifestyles that may help prevent some breast cancer cases and encouraging African-American women to utilize secondary prevention methods, such as mammograms, may reduce this mortality burden.

The Internet has become a source of consumer breast cancer information for many people, and the technology may offer opportunities to deliver tailored and targeted health education interventions that more effectively reach women in different demographic groups, including ethnic/racial groups, women with disabilities, and women facing other barriers to enacting healthy behaviors. However, in order to maximize effectiveness of interventions and breast cancer information Web sites, more needs to be learned about who among these groups seeks breast cancer information, why they seek it, what they want from a Web site, and what they do with this information.

This study acknowledges that beliefs about breast cancer and beliefs about the Internet both are likely to influence a woman's decision to search for breast cancer prevention information. Therefore, the project sought to discover more about how African-American women's perceived personal risk of breast cancer, beliefs about the disease and its prevention, beliefs about the Internet, and beliefs about the Internet as a source of prevention information interact.

This study does not seek to present a priori research questions to be tested by the data. Instead, as explained before, it proposes to develop a theory about African-American women's use of the Internet for breast cancer information based on women's experiences. Extant literature does little to inform this topic, certainly stopping short of providing hypotheses about the relationships under study or even clear indications of what components – Internet use, individual,

psychosocial influences on breast cancer beliefs, and perceived susceptibility to the disease, to name a few – should be analyzed in concert. Therefore, it was hoped that hypotheses about these relationships would emerge from the developed theory and will direct future research in the area. That said, the following serves as the initial and overarching question: Among members of these two groups – African-American women with breast cancer family histories and those without them – are their reasons for using or not using the Internet more related to their beliefs about breast cancer or to their beliefs about the Internet? The study's research questions are as follows:

RQ1: How do the women describe their beliefs about breast cancer and breast cancer prevention?

RQ2: What individual, interpersonal and cultural factors influence African-American women's beliefs about breast cancer prevention? What do they think breast cancer means to their communities? How do members of their social sphere and community talk about breast cancer?

RQ3: What emphasis do women place on personal, proactive breast cancer prevention information-seeking?

RQ4: What do they think about the Internet? How do they describe the Internet's role or importance in their social setting or community?

RQ5: What do African-American women think about the Internet as a source of breast cancer information? For women who use the Internet for breast cancer information, how do they describe their experience?

RQ6: What features or characteristics of the Internet enhance or deter women's experiences seeking breast cancer information?

RQ7: Among members of these two groups – African-American women with breast cancer family histories and those without them – are their reasons for using or not using the Internet more related to their beliefs about breast cancer or to their beliefs about the Internet?

CHAPTER 3 QUALITATIVE METHODS

This project was a sequential, exploratory mixed methods design with qualitative paradigm dominance. The study consisted of an initial qualitative exploration of African-American women's beliefs about the Internet as a source of breast cancer prevention information. This phase involved in-depth interviews with women between the ages of 35-60 years. Based on analysis of this qualitative data, a survey was created and administered to African-American women in the same age group to provide quantitative, complimentary exploration of the theory developed from the interview research. This section will describe the qualitative paradigm, mixed methods approach to research, survey research methods, and the proposed study design.

Qualitative Research

The qualitative research paradigm comes from a viewpoint that reality is subjective and multiple. There are many truths as opposed to the one objective Truth that is more common in the quantitative research paradigm. This study assumes that the women participating in the research have views of, ideas about, experiences with, and meanings for the subjects that are part of their realities.

Creswell (2007) cites the five philosophical assumptions about qualitative research as including ontological, epistemological, axiological, rhetorical and methodological. Ontology is "the nature of the things we seek to know" (Littlejohn, 2002; p. 28), and in the area of social sciences includes debate about actional and nonactional human behavior. This study reflects an actional perspective, assuming "that individuals create meanings, have intentions, and make real choices" as opposed to being ruled strictly by biological and natural forces (Littlejohn, 2002, p. 29). The women in this study were assumed to be part of an active social system, wherein they

make conscious decisions and have interactions with other people who are also making decisions.

As mentioned, part of the qualitative method ontological assumption is a subjective reality. The practical application of this assumption is that qualitative researchers present the participants' actual words to show their perspectives. Participants' words may be grouped by similarity into themes, but the themes are descriptive and not absolutes. These themes are not intended to represent a larger population's reality. In this study, rich descriptions of the data from transcripts were presented. This was done to ensure that the women's words were interpreted as consistent with their meanings. Also, it allows readers to understand, dispute, or agree with the emergent thematic groups.

Next in the list of qualitative method assumptions is epistemology, which covers "questions concerning the nature, scope, and sources of knowledge" (DeRose, 2005, ¶ 1). It considers the possible ways humans come to knowledge, either intrinsically or through their senses. Epistemological assumptions in qualitative research concern the relationship between the researcher and what is being researched. Creswell (2007) says that the researcher takes efforts to reduce distance between him- or herself and the research by interacting with the participants in the field. In this case, the researcher personally conducted the interviews with the women.

Axiology, the philosophical study concerned with values, is the next important assumption and involves the scientist's observational or participatory role in research (Littlejohn, 2002). Quantitative purists may believe that subjecting one's values to research – or subjecting research to the researcher's values – taints it, while others believe that the initial selection of any study subject is essentially a value-laden action (Littlejohn, 2002). The axiological assumption in qualitative methods requires the researcher to identify and present biases in the research by, for

example, reporting in the final paper both his interpretations and the participants' interpretations (Creswell, 2007). The section on study quality will discuss these matters more fully.

Rhetorical assumption asks about the language of the research. In qualitative research, the investigator may use qualitative terms and an informal style, including first-person pronouns.

This reflects quantitative research's basis in a science that seeks an objective Truth.

Methodological assumption is about the process of research. Qualitative research employs inductive logic that emerges from the study itself (Creswell, 2007). The grounded theory used in this study fostered this emergence.

Symbolic Interactionism

The underlying theoretical perspective of this study was symbolic interactionism. Lindlof and Taylor (2002) describe symbolic interactionism as "the study of how the self and the social environment shape each other through communication" (p.41). It reflects the idea that meaning ascribed to communication or a symbol comes from the context of the symbol's use. The meaning a person ascribes to symbols (concepts, words, etc.) is influenced by his or her experience with it, both personally and socially. This allows for and predicts different meanings in people and social groups, as well as a sense of dynamic, ongoing interpretation as new interactions are added, as is consistent with the qualitative research view of reality.

Associated with the work of George Herbert Mead (Charon, 1998) and explicated in Herbert Blumer's 1969 publication, symbolic interactionism is

...based on the notions that individuals act toward objects on the basis of the meanings that these objects have for them, these meanings arise out of social interaction with one's fellows, and these meanings are modified through an interpretive process by the individual (Rogers, 1994, p. 170).

As opposed to the idea that people's sense of self evolves naturally and "instinctively," Mead saw personal conceptions as being influenced by social processes (Rogers, 1994, p. 168).

Symbols are important because they represent shared meanings. Humans interpret symbols based on individually and socially determined ideas about the items. Religious artifacts are rather obvious examples of symbols because it is the ascribed meaning of the crucifix, for example, and not the material from which it was made that conveys significance to individuals. Language is another symbol, a very important one in the study of communication.

Charon offers some central ideas about symbolic interactionism. First is the notion that social activities among people are “dynamic” (p. 27). The dictionary definition of the word dynamic includes ideas of change, power, influence, and group roles and processes. Charon’s next four ideas reflect many of these definitions. He goes on to say that it is not only interpersonal interactions but intrapersonal actions that cause human actions (p. 27) and that people “define their situation as they go along in their action,” implying a continuous or cumulative process (p. 27). Next, Charon says it is the present circumstances and interactions with things in the present that cause people to take an “active part” in causing their actions (p. 28).

Symbolic interactionism has been the theoretical principle behind several studies of women’s perceptions of breast cancer treatments and risks (e.g. Halkett, Kristjanson, & Lobb, 2008; Halstead, 2001; Hoffman-Goetz & Mills, 1997). In the present study, the perspective allowed the researcher to view participants as active players in making meaning about the concepts in the study – health, disease prevention, media, the Internet, beliefs about life, and any number of potential symbols that arose from the study. The women make active choices toward these things based on individually and socially developed meanings about the represented items.

Appropriateness of Qualitative Design to the Study Topic

This study sought to answer questions about a topic that has not been well studied in its target population. More specifically, these questions have not been studied under the proposed

combination of a new media content access model and public health behavior determinant parameters. When there is little or no prior knowledge about a topic, qualitative inquiry allows researchers to gather data from participants in order to generate a theory about the concepts under study (Morgan, 1988). Morgan explained that qualitative methods are useful for “exploration and discovery,” “context and depth” and “interpretation” (1998b, p. 12). In this particular case, the literature review showed that the questions of why and how African-American women without breast cancer histories would seek primary breast cancer prevention information from the Internet have not been fully answered. Consistent with Morgan’s explanation of qualitative methods’ use, the study explored beliefs about seeking breast cancer prevention information in the context of a new media content access model. The research examined that question using in-depth interviews to gain insight from women in the target population about why they do or do not use the Internet for that purpose, followed by a quantitative approach to further explore the question. The qualitative design allowed the researcher to delve into three related areas of inquiry:

1. The meanings women make about primary breast cancer prevention and mammograms
2. The meanings women make about the Internet as a communication technology
3. The meanings women make from online information about breast cancer prevention

While these three lines of inquiry are somewhat ambitious for a single study, the purpose of this project was to understand two important and oft-studied subjects in light of one another. As this has not yet been done in the recent published literature, it served as a test of whether or not such medium theory-meets-research application studies can be conducted. First and foremost, however, it allowed the researcher to generate theory grounded in the data and possibly to use these findings to inform further explorations in this scholarship area.

Grounded Theory

Although this study recognizes and mentions some of the Health Belief Model's components, the investigation does not use that model as its theoretical underpinning because the researcher believed that the use of or intention to use the Internet for breast cancer prevention information might be influenced by more variables than are described by that model. Instead, the study developed a theory from the information collected in these focus groups, producing a theory grounded in the data.

Glaser and Strauss (1967) described grounded theory as a way of generating theories of social phenomena from emerging data observed or collected through social interactions. This qualitative method seeks to collect data, analyze it for themes or core concepts, and then collect more data to analyze in this light and integrate into the framework. The cycle repeats and eventually produces a theory based in the collected data. As Richards and Morse suggest, a qualitative method such as this is useful for developing theory based on reality instead of based on the researchers' biases or prior research that does not explicitly match the questions in the current study (2007).

The approach and interpreted meaning of grounded theory as a means of generating theory in research splintered after the early description by Glaser and Strauss. Since then, various versions of grounded theory research have emerged. One of those interpretations was the systematic process by Strauss and Corbin (1990). The grounded theory process begins by theoretical sampling – choosing participants who will help a theory develop – and then follows what Creswell (2007) describes as a zigzag pattern of collecting data from the field, analyzing the data, returning to the field for more data, and so on. New data are constantly being compared to existing data and emerging concepts; thus the term constant comparison is used to describe the process. Due to this cycle, the theory is based on inductive and deductive research approaches –

unveiling concepts from the data and then testing the fit of those concepts with new data (Green & Thorogood, 2004).

Coding Steps. Grounded theory processes begin with coding the data. The first coding phase is open coding, a step that applies the question “What is happening here?” to each line of the first pieces of collected data (transcript portions, in this case) and helps identify the core phenomenon being observed (Creswell, 2007). Strauss and Corbin (1990) refer to open coding as “the part of analysis that pertains specifically to the naming and categorizing of phenomena through close examination of data,” stressing that coding requires comparison making and asking questions (p. 62). Open coding deconstructs the data so they can be examined in smaller units. Each unit of data (words, sentences, or paragraphs) should be assigned codes or labels based on what it represents (Strauss & Corbin, 1990). Green and Thorogood explain that such an approach generates many potential conceptual labels that ultimately may fit or not fit the data, depending on what emerges from the rest of the collected data (2004).

Once some codes in the early data are established, the researcher should constantly compare new data units to see if they represent the existing codes or new ones. After the codes are established, the theorist begins to group related codes into provisional categories (Strauss and Corbin, 1990) that are given abstract names to represent them in order to be memorable. The categories have attributes, which Strauss and Corbin (1990) refer to as properties, and those properties occur along a continuum, identified as the property’s dimensions, that help researchers understand relationships between categories and subcategories. Attributes of the categories are referred to as subcategories. Subcategories include causal conditions, strategies and intervening conditions, and consequences of using the strategies (Creswell, 2007), all of which relate to and qualify the core category.

Axial Coding. In the next phase, axial coding, the researcher reconstructs the data “in new ways by making connections between a category and its subcategories” (Strauss & Corbin, 1990, p. 97). Relationships between labels are considered, and these relationships help the researcher understand some of the bigger picture concepts at play. For this to happen, the researcher may explore which codes are conditions and consequences of other codes, therefore mapping out a relationship between the codes’ context. After these relationships are provisionally made, the data must be consulted again to verify the appropriateness of the relationships.

Selective Coding. In the final coding phase, selective coding, researchers see core categories arise from the analyzed data, and they can start forming more abstract theories (Green & Thorogood, 2004) and develop hypotheses (Creswell, 2007). Strauss and Corbin describe selective coding as consisting of five steps: explicating the core story of the phenomenon in the form of a story line; explaining the relationship of the other categories to the core category; doing so according to “conditions, context, strategies, and consequences” (p124); and “validating relationships” (p. 128) the researcher made by checking it against the data; and finally to make refinements to fill in category gaps (p. 141).

Research Process & Interpretation Integrity. In qualitative methods, the researcher plays a key role in the research by his or her direct involvement with study participants by interviewing them, moderating focus groups of participants, and conducting deep ethnographic studies. The researcher’s presence likely influences whatever phenomenon is being studied, as her own biases will possibly affect her interpretation of the data. There are several concepts in qualitative methods that are employed to ensure high quality results and reduce researcher interference with the integrity of the study.

Researchers have suggested many qualitative-specific approaches to research quality that are similar to the aims of quantitative research's reliability and validity (Creswell, 2007). For example, Lincoln and Guba (1985) used credibility to refer to the research's value as it reflects the presented reality, transferability to represent the findings' application to other contexts, dependability to mean consistency, and confirmability as a reflection of neutrality. Lindlof and Taylor describe validity as a researcher's desire to "inspire confidence in readers (and themselves) that they have achieved a right interpretation" (2002, p. 240) of observations. Johnson and Turner use more general terms to represent validity, saying that it means "high quality research" (2003, p. 299).

Some of the terminology development by qualitative researchers may be interpreted by others as efforts to make qualitative research palatable to members of quantitative-dominant research fields; thus it may be discounted by qualitative purists. Creswell (2007) does not attempt to rename concepts; rather he reinterprets them in the form of methods qualitative researchers can use to ensure a level of research quality that rivals that of quantitative methods. He says validation is an effort to assess the findings' accuracy. Qualitative methods can achieve accuracy by spending a great deal of time in the field, using "thick descriptions" in reports, and by establishing relationships with participants. Creswell says qualitative research can be enhanced through triangulating methods, peer review of methods and interpretations, clarifying biases at the front end, and using external audits and member-checks. Keeping good records of these things may not only make results seem more "valid" to other researchers but it reminds the study's investigator to orient herself in the study as a strategic researcher. Reliability, according to Creswell (2007), is increased by the quality of field notes and transcribing, and by using multiple coders for the data analysis and a codebook, and finding stable agreement on the codes.

Mixed Methods

The qualitative research paradigm was described first because it undergirded the purpose and approaches used in the study. However, this study included a mix of qualitative and quantitative methods to explore the research questions more fully. The use of mixed methods in social science research is based on the notion of multiple ways to ask questions about social phenomenon (Greene, 2007). Mixed methods use a combination of qualitative and quantitative research methods, as opposed to multi-method studies that may use more than one type of qualitative method or quantitative method in one study (Tashakkori & Teddlie, 2003). Greene says,

A mixed methods way of thinking is thus generative and open, seeking richer, deeper, better understanding of important facets of our infinitely complex social world. A mixed methods way of thinking generates questions, alongside possible answers; it generates results that are both smooth and jagged, full of relative certainties alongside possibilities and even surprises, offering some stories not yet told (2007, p. 20).

In other words, using mixed methods allows for multiple pathways to understand complex ideas and to reveal unanticipated aspects of the studied phenomenon. This study type may also reveal connections between social processes and generate new theories about phenomena (Greene, 2007). Central to the justification of mixed methods research are the ideas that these different research angles may provide better understanding and that differences revealed by the methods are to be appreciated as opportunities for “embrac[ing] dissonance,” instead of opportunities to delegitimize one method (Greene, p. 23). Morse suggests both quality and efficiency justifications for mixed methods, saying that use of multiple methods gives us “a more complete picture of human behavior and experience,” allowing us to reach research goals for understanding the phenomenon faster than we might with only one method (2003, p. 189). Two different methods may also help overcome the obstacles or disadvantages inherent in each single method and answer questions that one method could not answer (Creswell, et al., 2003;

Tashakkori & Teddlie, 2003). Whereas mixed methods have comprehensiveness as a strength, their weakness may be a presumed lack of rigor. Use of clear data collection and analysis descriptions helps overcome others' skepticism about the study's rigor (Morse, 2003). In fact, the qualitative paradigm's techniques for ensuring high quality studies should reduce or eliminate concerns about rigor.

One of the important aspects of conducting mixed methods research is understanding that the differences in qualitative and quantitative methods extend beyond study design into philosophical schools of thought about how knowledge is generated (i.e. deductively versus inductively) and the construction of the social world. Quantitative pursuits usually involve a priori constructs and hypothesis testing whereas qualitative research seeks to allow the reality of human behavior to emerge. These stances influence the selection of inquiry methods. However, Greene (2007) points out several studies that suggest these kinds of epistemological stances are not always used in method choices, with the context of the problem being studied often influencing what methods are used. When using mixed methods, researchers may identify with one stance among many along the continuum of incorporating qualitative and quantitative philosophical assumptions. Each study's purpose will determine the underlying theoretical stance. For example, studies that seek to confirm relationships will be directed by the quantitative research tradition and deductive reasoning (Morse, 2003).

Research decisions are guided by research purposes, which is different from the research questions. The research purpose requires the designer to think about the reasons for the study (Newman, et al., 2003). In this dissertation project, the research questions – African-American women's beliefs about breast cancer prevention information on the Internet – are different from the underlying purpose of asking those questions, which is that African-American women with

breast cancer face worse mortality odds than white women; therefore interventions to encourage black women to take steps to prevent breast cancer may reduce a health disparity.

There are many reasons to mix methods, including triangulation, complementarity, development, initiation, and expansion (Greene, 2007, pgs. 100-103). In this study, the mix of methods will be used for complementarity and, to a lesser extent, development purposes. Greene describes complementarity as appropriate when the “study seeks broader, deeper, and more comprehensive social understandings by using methods that tap into different facets or dimensions of the same complex phenomenon” (2007, p. 100). With this purpose, one method offers insights that further and enhance the inferences from the other method. Development purposes are rather self-explanatory; they involving using a method to help design another research instrument. In the first phase of research, themes and statements emerge. They are used in the next phase to help the researcher identify questionnaires in the literature that are appropriate for use in the study or to develop new questionnaire items, although the difficulty of translating qualitative data analysis into quantitative question items is said to be one of the disadvantages of this approach (Creswell, et al., 2003). Development is described by this researcher as a secondary purpose to the study because the development concept implies that the first research phase may only be conducted in order to develop the instrument, placing more importance on the latter phase.

Mixed methods studies may be concurrent, with data collection through qualitative and quantitative methods occurring at the same time, or sequential, where one phase is completed before the other begins. Studies may begin with qualitative research first and then quantitative data collection, or vice versa. Each phase of data collection and analysis is completed separately

and then findings and interpretations are integrated at the end of the study (Creswell, et al., 2003).

Researchers using mixed methods can decide how to incorporate the philosophical stances of qualitative and quantitative research, treating the two methods as distinct but equal studies, each subject to its own paradigmatic assumptions, or putting more emphasis on one type of research for the study's interpretative lens. In studies where one method is dominant, the first phase's findings serve as the main theoretical base and the other method supplements the first (Morse, 2003). This study used a dominant-less-dominant stance in which the qualitative portion was considered more dominant than the quantitative (Creswell, 1994).

Designs may also be explanatory or exploratory in purpose. This study will use a sequential exploratory design, with the qualitative portion of the research being conducted first, followed by the quantitative method, with the purpose of exploring, not explaining, the phenomenon (Creswell, et al., 2003). This type of exploratory design is useful for exploring emerging theories from the qualitative portion by using a different research angle in the second (Morgan, 1998a). The symbols QUAL → quan signifies the direction of the research as well as the emphasis placed on each part (Creswell, et al., 2003). Sequential mixed methods designs beginning with qualitative phases first identify groups of similar people in the research and then use quantitative research to make comparisons between groups (Tashakkori & Teddlie, 1998). The quantitative portions of the study are used to add to the qualitative part (Steckler, McLeroy, Goodman, Bird, & McCormick, 1992).

Research Design

The research design involved recruiting African-American women for interviews, seeking a mix of women who had and did not have family histories of breast cancer and a mix of Internet users and non-users. Family history of breast cancer was an important distinction because

women with such histories tend to overestimate personal risks of the disease and therefore may have different health information-seeking patterns and different general approaches to prevention (Haas, et al., 2005). Internet use status was of obvious import; as the study was ultimately interested in the use of Web-based breast cancer interventions, it was necessary to understand why women do use the Internet and why they do not use it.

Interviews

Lindlof and Taylor (2002) say that “interviews are particularly well suited to understanding the social actor’s experience or perspective” (p. 173). Frey and Fontana (2003) distinguish between two extremes of interviewing approaches in structured and unstructured interviews by saying that in the first case, interviews ask the same questions in the same order to all the participants, but in the second kind, no “a priori categorization that may limit the field of inquiry” is imposed (p. 75). In other words, developing a preset interview guide would violate the spirit of unstructured interviews. A third, middle type of interview approach is the semi-structured interview. In these data collection sessions, the researcher has a preset interview guide based on questions sought to be answered by the participants, but the researcher can insert other probing questions to further explore a participant’s comments. The researcher may ask questions out of order if the participant’s answers to a previous question lead into a later one.

Lindlof and Taylor (2002) informally distinguish between structured and semi-structured interviews by describing benefits and uses of associated tools. Interview schedules are structured sets of questions that are asked of each participant in a specific order, so that the answers can be compared from one participant to the next. In this study, a less rigid interview guide was used. This tool represents a rough grouping of study questions and topics but does not require that the questions be asked in a particular order or even in the exact words on the page. Instead, the conversation dictates the question flow and can be adapted to the “verbal style of the participant”

(Lindlof & Taylor, 2002, p. 195). Semi-structured interviews with an interview guide were selected to allow for the interview to bring up insights and topics that the researcher did not anticipate when conceiving the design. This approach is more consistent with the proposed grounded theory method, which advises researchers to reduce personal and professional biases when conducting the research in order for new theories about the phenomenon to emerge.

The purposive sampling approach used in this study guides researchers to select participants for traits, experiences, or characteristics that will yield insight into the phenomenon's meaning, as opposed to using random selection techniques in hopes of achieving a representative sample. Lindlof and Taylor (2002) explain that it is appropriate to select individuals based on their experiential knowledge, including membership in a social category or status they are "[presumed to share] life conditions or challenges" (p. 173). In this project's case, race and age were two social categories and breast cancer family history and Internet use were two status variables for which the researcher purposively sought out participants for inclusion in the study.

Questions and prompts on the interview guides varied slightly according to which session was being conducted. For instance, all participants were asked about their reasons for using or not using the Internet for health information purposes, but the self-reported Internet users were asked questions specific to their experiences using the Internet for health information. The three categories of questions in the interviews were beliefs about breast cancer and prevention, beliefs about and use of the Internet as a general tool, and beliefs about the Internet as a source of breast cancer prevention information. Most questions were open ended and explored how the women make meaning out of the concepts of breast cancer prevention information-seeking and Internet use, with the hope that these resulting data would help the researcher begin to understand how

the social, cultural, interpersonal, and macro level factors might influence women's beliefs about seeking breast cancer prevention information on the Internet.

The research questions posed were explored using interviews of African-American women older than 35 who had not been diagnosed with breast cancer. This group was chosen because it included women who are near the age (age 40 and older) at which annual mammograms are prescribed as a course of secondary prevention, so that women who are approaching this age or have reached this age could benefit from primary prevention information now and screenings in the future. Another reason why the lower boundary for age was chosen is that the women would be the next age group of women to benefit from Web sites about breast health.

Of all the literature reviewed for this study, the most similar qualitative research design found was in a study conducted by Unruh, et al. (2004). They sought to understand what online breast cancer risk information women without personal breast cancer histories preferred, ultimately finding that women preferred sites from credible sources that offered personalized information and answers to specific questions. The research was conducted with focus groups divided by users and non-users of the Internet. Within the study, researchers asked what barriers prevented women from using the information. Three of these elements – women without personal cancer histories, online breast cancer risk information and the division of groups by Internet use status – were common to this study and yielded helpful direction in the methods section of this paper. However, the two studies diverged in four important ways: 1) Participants in this study were also divided by absence or presence of a family history of breast cancer; 2) African Americans exclusively participated in the interviews; 3) barrier questions concerned health beliefs and beliefs about the Internet; and 4) this study's methods were in-depth interviews

and a subsequent survey design based on the results of the interviews, instead of the cited study's focus group method.

Theoretical Sensitivity

Strauss and Corbin (1990) say that theoretical sensitivity describes the researcher's personal qualities, expertise, and experiences that may be factors in her interpretation of meaning in the research. They say it is "the attribute of having insight, the ability to give meaning to data, the capacity to understand, and capability to separate the pertinent from that which isn't" (p. 42). Everything from expectations for the study outcome based on those of prior research to the researcher's own professional and personal experiences may influence how she perceives meaning from the qualitative data. Strauss and Corbin (1990) say researcher biases can be checked by consciously throughout the study asking oneself if the data are really supporting what the researcher believes she is seeing in the data, by remaining skeptical, and by adhering to rigorous methods for data collection and analysis (pp. 44-45).

The author recognized the biases researchers can bring to qualitative studies, both based on her personal presence in the study and her expectations. In order to remain aware of the potential for biases and to try to limit their influences on the research, before gathering data, she described her relationship to the topic. First in the demographic category, unlike the interview participants in the study, she is younger and identifies as white. Similar to the interview participants, she has never been diagnosed with breast cancer. Second, related to the Internet use variable, the researcher is a heavy user of the Internet and regularly searches for health information as part of her job. She could not recall having ever sought information specifically about breast cancer prevention for personal reasons. The answer to this question was slightly surprising to the author, as she considered herself a proactive health maintainer. However, she recognized that she had been immersed in cancer prevention information since her mid-20s, when the researcher first

began working with cancer organizations and on cancer-related projects. Because she had learned about cancer prevention as part of her job, the researcher did not need to search for that information for her own health purposes. However, she does see herself as relatively proactive in terms of seeking health information and taking actions to reduce health risks.

Interview Method

The study recruited self-identified African-American women (Matthews, Sellergren, Manfredi, & Williams, 2002) from a large Southern city to participate in interviews. Local churches, businesses and community organizations served as the primary recruiting venues. Because this project was concerned with women who have no personal histories of breast cancer, identifying women through clinics or other health centers, as is often done in studies about breast cancer patients' experiences using the Internet for information-seeking, was not necessary.

A short screening guide was used to determine if a woman met the criteria for the study. Women were excluded from the study if they had had a personal diagnosis of breast cancer or if they did not meet the age criteria. Potential recruits with professional careers in medicine or public health (i.e. doctors, nurses, or similar professions as opposed to merely working in a hospital) also were excluded because these individuals are expected to have specialized knowledge about health that probably would influence their attitudes and beliefs about the subject. A short questionnaire was administered before each interview to gather demographic information about the participants. Questions included yielded information about the women's age, education, Internet use, and breast cancer family history. Although mental or cognitive functioning was not measured, women had to be able to demonstrate understanding of their rights as a participant as well as show a willingness to take part in the study. A consent form approved by the Institutional Review Board (IRB) and signed by each interview participant demonstrated her agreement to participate. The protocol submitted to IRB stated the parameters

of the study, explained how collected data would be used, and assured that the participants' identities would remain confidential (see Appendix A, with investigator's contact information removed).

The interview sessions were held in safe, quiet and comfortable locations of the interviewees' choosing, including a church, restaurant, and office building. In accordance with traditional sentiment in qualitative research, the number of interviews conducted depended on when saturation was reached and the data being collected no longer offered new insights on the subject; rather it repeated what had been provided in previous sessions. No new themes emerged after the first four interviews. The women repeated different versions of the same themes. For example, some women said they did not think they were at risk for breast cancer because they did not have a family history of the disease, while other women said they were at risk because they did have this history. In both cases, family history's association with perception of risk was the theme. The researcher continued to interview five more women in an effort to include many views and see if any more themes would emerge. However, no new themes emerged in subsequent interviews.

An interview guide for the sessions is provided in Appendix B. It outlines key topical areas that were covered in the interviews. Some of the questions were asked in every session, but others were presented differently or not at all with certain women. For example, questions about breast cancer prevention beliefs were relevant to every category of women, but questions about beliefs about the Internet were posed only to self-reported Internet users, inquiring why and for what purposes they use the Internet. Internet non-users were asked a variation of those questions to understand why they do not use the Internet.

CHAPTER 4 QUALITATIVE RESULTS

Summary of Interviews

Nine women were interviewed in-depth about their Internet and breast cancer prevention beliefs. These women represented age, education level, marital status, and vocation diversity. Table 4-1 shows the nicknames and key characteristics of the women interviewed. Those women with a mother, sister, or grandmother who had breast cancer are indicated by italics.

Interviews were conducted in places the participants suggested would be convenient and comfortable for them, including workplaces, a fast food restaurant, and a church. The interviews took between 40 minutes and a little more than an hour each. The sessions were recorded with a digital audio recorder and the audio files were later transferred to a computer and transcribed and analyzed in NVivo7 by the researcher.

Table 4-1. Women interviewed and their characteristics

Nickname	Age	Relationship	Education Level
Ada	42	Married	High School
Betty	56	Married	Some College
<i>Joan</i>	<i>43</i>	<i>Single</i>	<i>College</i>
Joyce	46	Divorced	Some College
Linda	43	Single	Some College
<i>Mandy</i>	<i>38</i>	<i>Single</i>	<i>High School</i>
Melissa	32 ¹	Married	Graduate School
Rachel	38	Married	Some College
<i>Tisha</i>	<i>38</i>	<i>Single</i>	<i>College</i>

Although the interview participants represented a range of ages, education levels, Internet use, and experiences with breast cancer, major themes were repeated with such frequency that after four interviews very little new information was presented in additional sessions. Subsequent

¹ One woman was found to be a few years younger than the initial minimum age level set but her interview was included because her education and perspectives represented characteristics that enhanced the study.

interviewees' answers fit within existing open-coded themes. However, the researcher continued to interview women who had different demographic and other attributes that might offer unique insights into beliefs about the Internet and breast cancer prevention, or allow the researcher to make stronger inferences about themes. After nine interviews, the researcher determined that the no new themes were emerging.

The next section of this chapter presents major themes and subthemes from the interviews. While not every theme addresses a research question, many of the themes do provide insights into the concepts asked in these questions. A summary of each research question and its answer from the interview follows themes and sets of themes.

Interview Themes

Breast cancer beliefs. This subsection of findings about breast cancer and prevention beliefs provides the qualitative data that support the summarized findings. In addition to women's knowledge-related beliefs about breast cancer, such as their beliefs that the biggest risk factor for breast cancer is family history, major themes found include proximity to the disease affecting beliefs, a focus on secondary prevention, and changes in social views and science of breast cancer. A final theme that permeates the other themes is a lack of knowledge about the disease and its prevention.

Beliefs about breast cancer related to the interviewed women's impressions of the disease's impact on other people, as well as beliefs about their own risks of developing breast cancer. For women whose families were not affected by breast cancer, the disease was a less concrete fear, meaning that the women thought breast cancer was scary and often associated it with bad outcomes, but they spoke from a position of an unaffected observer or commentator. For women who had mothers, sisters, or grandmothers who had survived or died of breast cancer, these personal experiences served as a basis for the women's beliefs about the disease.

These experiences carried over to preventive behaviors, too. The women who had experienced breast cancer in their families were more attentive to prevention strategies, such as screenings. Breast cancer prevention beliefs were also associated with the women's beliefs about breast cancer risk factors. Although some controllable risk factors, such as smoking and diet, were cited, the women mostly expressed the belief that breast cancer is an inherited disease; a woman's inherited genes determined whether or not she would get breast cancer. With this belief that breast cancer may or may not be a woman's genetic fate came a view of breast cancer prevention as almost entirely a secondary prevention domain function.

Inherent in the interview participants' beliefs about breast cancer was a perceived (and likely real) lack of knowledge about breast cancer, its risks, and its prevention. At times, this theme was represented by the women's own admissions that they did not know much about breast cancer; at other points, the lack of knowledge was apparent in that the women espoused myths about breast cancer causes that leading cancer organizations dismiss as scientifically inaccurate.

Proximity to breast cancer influenced women's beliefs about breast cancer. When first asked what breast cancer meant to the interviewed women, differences in perspectives based on experience were immediately evident. Women who did not have family histories of the disease answered from a knowledge or fact-based angle, such as Joyce who said breast cancer meant "like a lump or a mass in the breast," Linda who initially answered with a definition, "Having, uh, a cancer of the breast. Being checked for it," and Betty, who associated breast cancer with its impact on women more than men. Ada similarly thought of breast cancer as the diagnostic process and common treatments and outcomes, saying, "I think about you having your

mammogram and they find a knot or whatever, and you get it tested and if it's cancer, then they tell you what you need to do...chemo. Having your breasts taken off."

These definitional or process answers given by women who had not experienced the disease's effects from a close vantage point reflected perspectives of looking from the outside in on what breast cancer would be like. Contrasting this perspective was that of women who had been on the inside of their family members' breast cancer battles and used that experience to anchor their responses. For example, Mandy said, "Scary. It's been in my family. My mother, my aunt...and others. So it's kind of a scary thing." Even though several women without breast cancer family histories cited fear of negative outcomes and side effects, such as Rachel who thought of her hair falling out and, "dying, um, it's just, it's just something I can't explain. Um, it's. . . it's not a good feeling," women who had not experienced breast cancer in their relatives spoke more abstractly about what they had heard or read about the disease, rather than what they had witnessed up close.

Proximity was a key theme in women's beliefs about their personal risks of breast cancer. This concept related to the women's perceived personal risks and the reasons they sought prevention. Overwhelmingly, the interviewed women framed risk of breast cancer in terms of family history of the disease. The women who had close relatives with breast cancer indicated a higher degree of perceived personal risk, whereas women without this family history mostly characterized their risk as low, citing the belief that breast cancer is largely inherited.

Ada, whose only family members with breast cancer were in-laws, said:

Um, I never – it's not in my family, my immediate family, so I really – I feel like you're kind of safe if your mother haven't had it or your grandmother, or you know, sister. I feel like – I don't worry about it, you know. I mean, I've had mammograms but I don't worry about it. I guess I figure if it's in the family, you'll get it, but if it's not, you won't get it. I'm not saying you can't, but I wasn't concerned because it's not in my immediate family, so...

Melissa, also from a family without breast cancer experiences, related this history to her own risk. She said, “So I think I have a low risk simply because no one in my family has it or no one has been diagnosed with it just yet, and I know that there are certain things that are hereditary. And I’m assuming that breast cancer may be one of them.”

While most of the women who had not experienced breast cancer in a loved one said they had not really thought about their risk, or they thought the risk was likely low, the women who had this family history expressed that they had thought about the disease’s impact and potential risk for them. Joan, whose family included several breast cancer diagnoses, said she based her risk perception on research or conversations with physicians. She said, “I guess I have to agree with the doctors and statisticians. I guess I have to say the genetics.” She said that family history likely increased her risks but that a combination of a healthful lifestyle and diligence in terms of checking one’s breasts and getting mammograms did not make a breast cancer diagnosis an inevitable event for her, explaining,

My own risk? I believe it could be high because of the genetics and because it’s so strong in my family. Like I say, on my mother’s side. But I guess I’m not really worried about it because I’m trying to take, you know, precautionary measures, trying to get my mammogram, eat healthier, and exercise more. And I do self-examinations every month. So I’m trying to stay on top of things.

Women with family histories incorporated their family members’ experiences into many of their answers about breast cancer beliefs, including their assessments of breast cancer risk factors. When Mandy, the daughter of a survivor, was asked what she thought put women at risk for breast cancer, she discussed her mother’s health and the absence of things she thought would increase risk:

I don’t know because it’s like when my mother was diagnosed with it, she didn’t smoke and I had heard – when I think about cancer in the first place, you know, I think about smoking. It’s just a, it’s just a gene or something, that [breast cancer is] all in my family.

Mandy's comment about smoking being a risk factor for breast cancer but not one her mother had when she was diagnosed shows how women with close proximity to the disease filtered their beliefs about risk and prevention through their existing schema developed through their loved ones' experiences. Mandy's own personal perception of breast cancer risk was "kind of high" due to an awareness that she has "a sensitivity to breast cancer because of my mom," however, she also expressed religious faith that her fate was not determined only by genetics, saying, "But I do think that just because my mother, my aunt, and my cousins had it doesn't necessarily mean that I'll get it, too. ... I'm a believer in God, and I don't have to have breast cancer."

Also consistent with the theme of proximity to breast cancer affecting one's beliefs about the disease was an example of a participant's friend developing breast cancer despite not having any of the risk factors – family history and smoking – the participant associated with the disease. Betty's schema regarding breast cancer risk may have been violated by this friend's experience.

Although Betty maintained a belief that breast cancer was hereditary, the story of her friend, who did not have the cancer in her family, made Betty think, "it could happen to us." The effect of this experience on Betty's perception of risk is complicated by the fact that she had had some suspicious mammograms in the past and thus seemed to have thought about her personal breast cancer risk more than the other women who did not have family histories of the disease. Both the friend's experience and Betty's own breast cancer scares put her in closer proximity to the disease. Of her own risk, Betty said:

I think it's a possibility. Like I said, I've had a couple of personal scares. I've had a mammogram that came back suspicious twice, actually. And had to have a biopsy, but it was fibroid tumors and so...nothing, no cancer was found. But I think that the possibility is – I wouldn't count it out. I wouldn't say that I have a great possibility, but I wouldn't count it out.

Perception of risk seemed to affect women's breast cancer prevention behaviors. Women who did not have family histories of breast cancer reported that they had had at least one mammogram in the past,² but they described the screening behavior in more casual, routine, and less urgent terms than the women whose female relatives had had breast cancer diagnoses.

Tisha's mother had breast cancer. She described her mother's ordeal of surgery, medication side effects, and getting a prosthetic bra, and the effect of that experience on her personally:

For me, it was scary. I was hurt like it was me. You see what I'm saying. So that threw me into checking myself every month. Being paranoid, I overly checked. I mean, I checked every day, you know. But you would have thought it happened to me, you know.

Tisha's experience and view of screening importance was echoed by the other women with breast cancer family histories, who often referred to their relatives' tumor detection and their perceived personal risk as prompting them to seek screenings. The women who did not have the same proximity to the disease stated very different reasons for getting mammograms and doing other breast cancer checks. Simply put, these latter women had had mammograms because the tests were convenient (and sometimes free) and/or because getting mammograms is something a woman is supposed to do when she reaches age 40. For example, Joyce said of her personal physician:

She – this is my regular doctor that I've had since probably I was like in my 20s or something. And I would go every year to get a checkup and when I turned 40, she was like, "Okay, it's time for you to go have your mammogram done." And, okay, I've had one mammogram done.

When asked why she had the mammogram when she did not think she was at risk for breast cancer, Linda said she did it because "the doctor sent me over there":

² Each woman's physician should have instructed her about how often she needs to have mammograms. However, if the general guidelines of every one to two years were applied to the women over forty in the study, each should have had at least two screenings by the time the interviews occurred.

I had it done because they say at age 40 you need to have, um, a mammogram, and I just went and had a mammogram, and they said ‘check your breasts’ and I checked my breasts and said, ‘No lumps,’ so...I just don’t do it. Which I need to. And I’m at fault for that. I’ll own up to that part.

In the last few sentences of that quote, Linda brought up an interesting point that low perceived risk plus an initial mammogram that detected no tumors may have actually reduced her perceived risk further by confirming that she did not have a problem (at the time). Two women, Linda, 43, and Joyce, 46, who both had had mammograms upon turning 40, did not have regular mammograms after that age. When prompted about why they did not have more frequent screenings, the women said they did not know how often mammograms were advised and believed that the doctors would likely have told them if they needed more tests. Again, this notion related back to the women’s beliefs that risk was tied to family history.

Focus on secondary prevention. The interview participants were asked what things they believed could prevent women from developing breast cancer. Even though the question’s terminology implied primary level prevention – ways women could avoid ever getting the disease – women’s answers always included secondary prevention such as screenings and tests. In fact, none of the women answered the question about preventing breast cancer with only primary level steps; if a woman mentioned healthful eating or another primary behavior, she quickly moved on to describe secondary prevention actions and usually spent more time describing prevention behaviors on this level.

Support for this idea comes from analyzing the women’s answers and the amount of time devoted to each type of prevention in their comments. Tisha, whose mother had breast cancer, is an example of this (for word count purposes, frequent “ums” were removed from this answer). She said a person might help prevent breast cancer by, “Eating healthy. Of course, making sure that you check your breasts. Prevention-wise, I guess it would be probably just getting checked,

you know?” Two of 23 words related to primary prevention and the rest were about secondary detection of breast cancer. Echoing the inference that actually getting breast cancer might be fated by genes, the participant wondered how much a person could really do to prevent the disease if she had genes predisposing her to developing breast cancer. Tisha said,

I guess to treat myself healthy and make sure I get regular checkups, um...um, you know, as far as that goes, I mean, I can't say that even if you did it, genetically if it was to be, it would be.

Answers like this supported the connection between inherited genes and risk. If one believes her risk is determined by her DNA, she may believe the disease's development cannot be prevented. In that belief scenario, the level of prevention shifts from thwarting tumor development to detecting it early enough to save the woman's life.

Joan, another participant with a family history of breast cancer, also emphasized awareness, eating healthfully, and getting tested for cancer. She devoted 16 words each to primary and secondary level preventions, saying, “I think diet and nutrition is part of it. And education is a part of it. And, like I say, mammograms. And other – whatever other means of early detection that's out there.”

Joyce pointed out some primary level prevention behaviors but emphasized secondary actions, including checking for signs of cancer and being screened:

I think like eating healthy, you know, watching your diet, you know, taking in the information of what you need to do, whether that is with your doctor or checking on the Internet what symptoms, you know, like doing your checkups, breast checkups, like they tell you to do at home, like when you go to the doctor's office, they would do it, or either, you know, doing your mammogram.

Betty came the closest to a pure primary level prevention answer to the question about preventing breast cancer by emphasizing diet and exercise. However, she also mentioned noting changes in your body and acknowledged that this concept was a secondary level of prevention, one that relates to the cancer already being in the body.

You know, as far as with diet and exercise. Things like that. And uh, just knowing your body and knowing when there's something that has changed in it that needs to...and I know that's still kind of saying, "Okay, it's there" but as far as prevention, it's been more like diet and exercising, so forth. And different foods that you can eat that can help you prevent cancer.

Other answers were much more overtly focused on secondary prevention. Clearly expressing this view of prevention as secondary was Linda's answer: "Either they can prevent it longer, prolong it, prolong their life or they can eventually die from it." And Melissa reiterated the idea that preventing breast cancer means finding problems early: "I think of a mammogram when I think of breast cancer prevention."

It is important to note here that all but one of the interviewed women reported that they had had a mammogram at least once in their lives, a factor that might affect their perceptions of breast cancer prevention. The one woman who had not had this screening test was younger than 40, the age at which guidelines recommend most women begin regular screenings (NCI, 2002). Even women who said they did not think they were at risk for breast cancer said they had received a mammogram, either because their regular doctor said they needed to have one at that age or because a free mammogram service was offered. The quotes below illustrate the similarities among descriptions of prevention expressed by five of the women:

Linda: "Self-check every month and before your cycle and after your cycle. They say to check in the mirror. And still do your annual breast...whenever you have to do your mammogram, kind of keep your appointments."

Betty: "Um, the self-examinations, um, regular, I guess at least once a year at a certain age for mammograms and make certain that they do that on a regular basis. And just be as knowledgeable as possible about what to look for."

Mandy: "Mammograms, um, self breast exams, go to the doctor. Basically just get the mammograms when you're supposed to and go to the doctor....Exercising and I just, basically, most of the women that I heard they do the tests, just the proper things to prevent it like the mammogram and the self breast exam. So I'm a real believer in the mammograms and the self-examining your breasts."

Joyce: “Um, eating healthy, um, get your mammogram done to check and make sure that you’re not, you know, forming breast cancer, and so forth, like doing the self-checks at home. You know. I forgot how they told me to do it at home because I don’t really do it but, you know, I’ve thought about the self-checks at home.”

Joan: What do I think about? Self-examination, early detection, for myself, because it was a while before I even, um, (started) to get mammograms because they was asking my history and finally, I think, somebody finally noticed that how strong it was on the maternal, on my maternal side. So they started me at age 30—how old was I? Thirty-four? Or maybe younger, between 33 and 34, because I know there’s a certain age but because of my family history, they didn’t want to wait. They started me immediately. So I get – I have a mammogram every year.

Changes and advancements in cancer treatment. At the beginning of this research question’s findings section, the researcher asserted that proximity meant something more than geographic or genetic closeness to breast cancer; it also was associated with prevailing and distinct social norms and scientific paradigms concerning the disease. Many of the women in the age group interviewed were part of generations that had seen notable changes in how society and science treats breast cancer. Some of the women made clear distinctions between the taboo ascribed to breast cancer by older generations and the more open advocacy efforts in younger generations. Most discussion of this theme will be presented later in the chapter. However, to the extent that interviewed women’s beliefs about breast cancer were associated with improved technology, awareness, and trust in screenings to increase survival, the theme will be described here, too.

Betty offered a good example of beliefs associated with social and scientific changes in breast cancer perspectives. She said,

I think there’s a lot of research available. I think that there are a lot of things in place now that have – more and more every day the technology is increasing to the point that I think, you know, that there are better chances to prevent it and um, I think that doctors are more knowledgeable and I think overall that people are more knowledgeable because it’s in front of them. People are constantly – you’ve got commercials, you’ve got Race for the Cure, um, you’ve got those types of things in place, too, as a constant reminder of the importance of self-examination and just preventing it if you can. And if not be able to prevent it – to catch it as soon as possible so that your chances of survival are far better.

Although women believed that breast cancer might be unavoidable due to genetics, they placed some hope in technology and medicine to make the disease survivable. In other words, as Betty put it, “If [secondary prevention] doesn’t prevent you from actually getting cancer, it prevents you from being a statistic – a death statistic.”

There was a sense of women being able to look back in history to associate breast cancer with death, while also looking at the present and future’s advancements in the ability to reduce breast cancer mortality. Two women’s comments illustrate this point. First, looking back, Joyce said that when she thought about breast cancer, she thought of “just so many people having cancer and ending up dying from it and stuff like that.” Similarly, Melissa said, “Most people I have heard of who have had breast cancer usually die before it is treated.” Despite their answers to the associative, first-thing-that-comes-to-mind inquiries, these and other women explained that they thought improvements had been made in cancer treatment so that diagnosed individuals might not die from it. Within their explanations of this change were stories of friends and family members who had survived different types of cancer.

Ada described two in-laws who had breast cancer, saying,

The mother had to have her breast taken off, but the aunt, they was able to get it out and save her breast, so I know there’s different ways that you can deal with it. You know, um, the one that they was able to get, get it out, she had chemo and the other one did, too, but they’re both doing fine. So I don’t think of death, you know, now. I used to, but now that I know somebody that’s been – you know that’s dealt with it for years, then I know there’s a possibility that you can live longer.

Similarly, Betty said, “Just the word ‘cancer,’ when you heard it usually you associated it with death. That when the person was diagnosed with cancer, no matter what form it was, they were going to die of it.” However, her husband had survived a form of cancer, and she cited him as an example that cancer “used to be a death sentence” but she had this example of overcoming the disease with today’s medical treatments.

The words “used to” demonstrate the women’s belief that cancer experiences are not what they were many years ago. Even Mandy, who lost her husband to colon cancer, spoke of changes in treatment offerings in terms of her experience with him.

When I think of cancer patients, I think of – I used to think, until my husband died of colon cancer – I used to think of people’s hair falling out. But now they have some things with cancer that make your hair grow. You know, treatment for cancer that make your hair grow even more so.

Several others interviewed said that technology and scientific understanding of cancer has changed over the years, perhaps leading to different outcomes for breast cancer patients today versus patients who were diagnosed in previous generations. Tisha reflected on her mother’s breast cancer diagnosis 15 to 20 years earlier, noting that in her mother’s case, the doctors had conducted the biopsy and mastectomy in a single surgery. “Who knows if that nodule was, uh, that could have been caught before then. I think there’s better technology now,” Tisha said. She compared the decision to remove her mother’s breast to a less invasive approach she believed might be more common today: “Even back then, I don’t remember people talking about radiation then, because they do that a lot, now before they actually say give somebody a mastectomy.”

In an earlier quote, Betty explained that she thought women’s chances of surviving breast cancer were better now than they were in the past. She cited advancements in many aspects of cancer control as well as awareness events as contributing to better outcomes. Joan described changes in technology that were not available when a family member was diagnosed with the disease. “It seems like there is more technology today than there was what seven, eight years ago. And I’m glad – I mean, it’s bittersweet because you know how the mind is, you’re like, ‘Okay, it wasn’t here around when she needed it, but I’m glad somebody is benefiting from it today.’ ”

Lack of knowledge about breast cancer and prevention. As some of the earlier parts of this section hint at, the women's beliefs about breast cancer often contained misinformation or incomplete information about breast cancer. For example, several women did not know how often mammograms should be performed. Women said they did not know how often they needed to have the test done or even if they needed to have subsequent mammograms after the first one detected no tumors. For instance, Linda said:

To be honest with you, I don't know if mammograms are done every year, every two years; I just know they get them at age 35 or 40, something like that. I had did them two times. But I hadn't had it again and I just turned 43 this year. So I know I hadn't had one in about two years.

Lack of knowledge is a tricky belief theme because the phrase implies a comparison between one person's truths and an objective standard. However, this subtheme is appropriate in a discussion about beliefs for two reasons: one, the women's answers to questions about breast cancer beliefs sometimes included expressions of doubt or lack of knowledge, such as Ada, who said, "I don't really know what causes breast cancer," and Linda, who said, "Really all I know is that it's just breast cancer. I don't know what causes it." Two, science does offer some clues as to breast cancer etiology. At the time of this writing, many questions remain about the disease's risk factors and causes, but extensive research has offered women some preliminary information about risks and prevention. Many of the women interviewed in this study did not report to have basic information about breast cancer. For example, none of the interviewed women suggested a connection between growing older and developing breast cancer, even though age is the second biggest risk factor besides being female. Also, by consistently citing genetics, they seemed to emphasize the association between family history and breast cancer diagnosis.

Even though a few women – Betty, Mandy, and Tisha -- mentioned smoking as risk factors for cancer, and Rachel mentioned overweight, the women almost always reported that they

thought family history determined risk or that they did not know what increased risk of the disease. Rachel was the only woman who reported common myths, including wearing bras and “men grabbing on your breasts.”

The lack of knowledge about breast cancer risk and causes carries over to a lack of knowledge about prevention. This makes sense, as someone who does not know what causes a disease would not know how to prevent it. Rachel said she did not understand breast cancer causes but would be pleased with outcomes and positive emotions associated with prevention, saying, “Prevention, it sounds good because they’re – it makes me feel like, you know, the women have hope. But it just seems like, I don’t know how you get breast cancer but prevention does sound good.” Similarly, Ada seemed familiar with the idea of prevention, even though she did not understand what it was or if it was really possible. She said,

I’ve been at health fairs, at [place of employment] and at different places and I would pick up a brochure and look at it. But I couldn’t tell you anything that somebody’s told me how to prevent breast cancer because I’ve never known that there was something that just caused it. I just thought there was something in your body or was hereditary. I didn’t know there was something you could do to get breast cancer.

This last sentence was the major theme in the study. The women’s association of risk with hereditary genetics – something that is, at the time of this writing, unable to be altered – moves the level of prevention from primary to secondary, except in women with genetic risk factors who elect to have preventive mastectomies without being diagnosed with breast cancer. Throughout the interviews, the emphasis in women’s answers to questions about breast cancer prevention was not about avoiding the disease, rather about avoiding death from it.

Answers to Research Question 1. These themes shed light on Research Question 1, which asked how the women describe their beliefs about breast cancer and breast cancer prevention. The women described beliefs both in terms of what they knew about the disease itself, such as breast cancer being a lump in one’s breast and the disease affecting more women

than men, and its impact on women, especially women they knew personally. They described risk as relating to uncontrollable genetic factors. Inasmuch, women with breast cancer in their families seemed to feel more susceptible to the disease than women without this risk. Due to this focus on genetic predisposition to breast cancer, the women interpreted prevention as early detection screenings that do not prevent developing cancer; rather the tests reduce mortality by finding cancers when they are more treatable.

Community Beliefs and Interpersonal Communication about Breast Cancer

Experiences with breast cancer influence communication about and the communities' views of the disease. The main influence of breast cancer beliefs in the interviewed women was experiences with the disease, including having loved ones who had faced it or having had a mammogram that spotted something suspicious. Breast cancer was seen as less of a problem in the women's communities compared to other diseases that were more prevalent. Although many of the women who did not have family histories of breast cancer said they did not talk about the disease, their reasons were that it had not affected them or their friends; therefore the topic had not come up in conversations. While the women described some negative connotations of breast cancer held by some in their communities that had once made the topic taboo, the women also recognized a shift in the way breast cancer is viewed and talked about due to awareness efforts that may de-stigmatize the disease and medical advancement in treatment and detection that increase survival rates. Witnessing changes in medical technology, various cancer outcomes in people they know, and seeing more emphasis on awareness messages may have developed (or prompted shifts in) women's beliefs about breast cancer prevention.

As the first finding – that women's perspectives of breast cancer were influenced by their family members' experience with the disease – has been described in answer to Research Question 1, the findings in this section primarily address the other social and community themes

revealed by the research. Those themes are 1) the tendency to measure the importance or priority of diseases based on how many people in the community are affected by them; 2) the spectrum of breast cancer perspectives from ascribed taboo, embarrassment, and moribund qualities on one end, to awareness, increased survival, and advocacy on the other; and 3) the notion that interpersonal conversation about breast cancer occurs in the context of someone the women know having the disease.

Disease priority relates to quantity of observations. The women seemed to determine “problem” priority based on pervasiveness of the condition as opposed to severity of effect on people’s lives. Mandy, who personally believed breast cancer was an important issue because it was pervasive in her family, still said it was less common in her community than other diseases, “like diabetes, high blood pressure, because I know a lot of people that have diabetes and high blood pressure.” From the interviews, it was evident that other diseases and problems were more common in the women’s communities, and the women suggested that the more common a problem is, the more it was talked about and the more serious it is. High blood pressure, heart problems, and diabetes were mentioned by almost every woman interviewed.

Mandy’s explanatory phrase “because I know a lot of people” indicates an association between ranking particular diseases as priority problems and observing how many people are affected by the conditions. Tisha reinforced this idea that the importance of a disease relates to prevalence in the community. Because breast cancer was less prevalent in her community, it received less emphasis. She said:

Because like right now, a lot of people are just more concerned with heart conditions and stuff like that. High blood pressure. That’s the more thing that people are talking about as far as being more out open than they would breast cancer. Nobody would...nobody sees [breast cancer], it’s like I said, unless it happens to somebody or something like that.

Melissa also brought up the idea that problem severity is associated with personal exposure to

the problem in the community,

High blood pressure and strokes...because we've had people in our community who have suffered from high blood pressure. A lot of family – a lot of my family members have problems with high blood pressure. And we've had people who have either um attended our church or are attending our church now who have had strokes. And I also have a grandfather who died of diabetes....I would say [breast cancer is] mainly last on the list.

Betty said something very similar:

As far as like hypertension and heart disease and strokes and things of that that nature...amongst the people that I know, I know more people who have high blood pressure, so to speak, certainly than I've known who had breast cancer...So I know that breast cancer is important, but I personally know more people are hypertensive and so forth than I know who have been stricken with breast cancer.

Spectrum of breast cancer perspectives based on advocacy and scientific progress. A previously mentioned finding suggested the influence of individual proximity to breast cancer on a woman's beliefs about the disease. Similarly, generations of people may have beliefs influenced by their proximity to changing social norms about breast cancer and scientific advancements in cancer treatment and detection. Even though the interviews resulted in a range of interpretations about how communities approached cancer topics, the answers reflected past versus present and old versus modern views about the disease.

The past themes involved breast cancer mortality and embarrassment about having the disease. On the other end of the spectrum were the present themes, including a belief that eliminating the problem of breast cancer means making people more aware of the disease and supporting and encouraging breast cancer patients and survivors. By past and present, it does not mean that the associations of death and shame with breast cancer beliefs are extinct. The interviewed women, however, drew distinctions between two disparate views and suggested that the advocacy, openness and awareness theme correlated with social and scientific changes younger generations associated with the disease. Of note, the women did not always clearly identify their own places along the spectrum of community beliefs.

Past views. Women said the low survival odds for breast cancer in the past had shaped community members' association of the disease with a death sentence or very negative side effects of treatments. This association had several effects. One was that some people thought only bad people got the disease. The second, and likely somewhat related issue, was embarrassment by those people who had the disease and fear of lost social support. The third mentioned outcome, also related to the first two, was that people did not talk about breast cancer.

Fear of breast cancer is still very common today (Wider, 2005), but the women's assessments of past views of breast cancer included a strong sense that lack of knowledge about the disease and myths about the disease striking people of bad character likely enhanced the past's fears of cancer. The difference seemed to be that whereas women now may fear getting cancer, in previous generations, there may have been a stigma of the complicit victim; that the women did something to get breast cancer.

Betty said:

... especially the generation that's just before me and the generations before that, for some reason or another, cancer was like something that only happened to bad people. So there was a...it was hush-hush. It was like you had the plague, but it was something bad you had done, and I don't know where that came from. But I know that I have experienced it with some of my older relatives, that they were – that it was just “hush-hush” because [whispers] “They've got cancer,” the C-word. And it was like it was a curse instead of something that could happen to anybody.

Betty and Ada both used the term “hush hush” when describing how people once viewed breast cancer. Ada's comments highlighted the possibility that the short- and long-term side effects of cancer treatment might be another aspect people did not want to think about or discuss:

I just remember people – it was kind of quiet, you know. “You know such and such's wife has cancer?” [Ada whispered]. And it was kind of like you really didn't talk about it. You didn't say – any kind of cancer.

Whether the stigma about cancer stemmed from beliefs that a person who got it was inevitably going to die from it or that the side effects of treatment were embarrassing, this view of cancer as a taboo subject affected how people talked about the disease.

Tisha shared that she thought fear of cancer, a lack of knowledge, and people's association of the disease with death likely affected women's views of breast cancer prevention. She said:

I think they're scared. They feel like – some people now might think it could be the end of your life, per se, as far as like, if it happened to you (at a) younger age, they might think you can't get married, you know, that you can't do this or that.

Rachel expressed a similar opinion about people's views of the outcomes of cancer: "A lot of black people, when you say cancer, they just stop and act like you're going to die."

The mortality concern was one of several reasons cited for why women would not be inclined to talk about breast cancer. Others were fears of losing social support during the treatment, embarrassment about side effects, and the desire to protect one's health privacy.

Representing the social fears about breast cancer was Joyce's comment about women's fears that they will lose social support systems if they get cancer:

Sometimes family members...you know a lot of people are scared of the word "cancer." And a lot of people don't—you know, they tend to shy away from you so you don't have that support if you actually did end up and have breast cancer or something.

Ada thought that people were reluctant to talk about breast and prostate cancer because sexual side effects for men and mastectomies for women were common and embarrassing outcomes of treatment. And Joyce felt that women with breast cancer wanted to keep the condition private because they would "probably think that people will treat them different, or talk about them like, 'Oh, you know, they done lost this weight and they had to have this done.'"

Linda actually shared an experience that supports Joyce's suggestion. Linda learned how important it was for a friend with breast cancer to contain and control who knew about her health.

And since [getting cancer], my friend had to have her breast taken off. And what happened, I thought I had done something bad, I told her ex-husband's mother that she had a mastectomy and she called me and blessed me out, said, "You shouldn't have told them I had one of my breasts removed." She was embarrassed.

Speaking further about this experience with her friend, Linda explained that the incident had ended their friendship. "She wanted to keep it quiet – she didn't want nobody to know. Like it was a secret," she said. Joyce also suggested that women who did not talk about breast cancer were probably embarrassed "or ashamed."

Advocacy and Openness. Interviewed women often referred to progressive views about breast cancer, even if the older views about death and embarrassment persisted in their communities. Comments about increasing awareness, participation in cancer charity events, and interpersonal communications about breast cancer were much more common in the women who had family histories of breast cancer. That subgroup of women's conversations will be discussed later. However, it should not be assumed that lack of conversation or awareness of breast cancer is related to beliefs that the disease is taboo.

Many of the women interviewed responded to a question about how women in their communities talked about breast cancer with a simple reply like Linda's answer: "We do not," Melissa's answer, "We don't discuss it really at all, or very much," or Joyce's, "We don't. We never have." These women all had the same answer to a follow-up question about why they did not talk about breast cancer: the disease has not affected them or their friends or family members. As Linda explained, "You talk more when it happens to you. You get more involved if it's you or somebody close to you." Similarly, Tisha said she and her friends are open to discussing breast health. "I have talked to lots of people my age in the community about fibrocystic disease, not breast cancer itself," Tisha said. Fibrocystic disease is very common in

her peer group, whereas with breast cancer, she did not “know a lot of people who have been affected by that” besides her mother, who is deceased.

Within the subgroup of interviewed women who did have family histories of breast cancer, the theme was consistent with the idea that people think and talk about conditions affecting themselves and their loved ones. “It is open and told,” said Tisha, whose mother had breast cancer, as did Mandy and Joan’s mothers. These latter two women shared similar views. Mandy said:

It’s not a sensitive subject. After my mom was diagnosed, her first-born niece was diagnosed with breast cancer... It’s kind of like, it’s not a delicate subject. We can talk. It’s not a sensitive subject for us. It’s okay. We can talk about it.

She spoke of a breast cancer survivor aunt’s advocacy within the family. The aunt, “who is still living, um, she has educated us a lot about breast cancer and breast cancer awareness and precautions and such.” She reported that one of the reasons female family members talk about breast cancer frequently is to encourage each other to get mammograms.

Joan also attributed conversations about breast cancer to the fact that her family has experienced it first-hand.

We communicate a lot anyway and because of the fact that it has occurred so much in our family... So it comes up. I mean, we don’t talk about it much because we’ve discussed it for so long. I mean, we’re comfortable with it. You know, there’s no tension, there’s no problem talking about it or discussing it.

Even women who did not have family histories of breast cancer serving as context for talking to their relatives about the disease had noticed changes in society and their communities’ views of breast cancer. Ada thought the changes in her local community’s approach to breast cancer communication resulted from having people in the church congregation affected by the disease. “My church is pretty open with it,” she said, and described the church’s participation in several health fairs and breast cancer awareness events. In the larger society, Ada attributed some

breakdown of the taboo to increased survival and to increased attention to cancer among famous people. She said,

I think a lot of things that's...you know, people are living longer, you hear good things; the cancer walks. Um, people talk about it – celebrities – I mean, people are really talking about it. They're more open about it. Um, I think you know, it's not whispered. And it could be because of the years. You know, but it's not whispered anymore. They just talk about it like any other sickness now.

Betty, who earlier had mentioned the older generation's take on cancer, also spoke of the openness about cancer due to experiences with it by people in her community. These individuals, according to Betty, are using their experiences to help educate others about awareness. Betty was involved in a church health ministry that included breast cancer education events. She said:

I know that it is very important to get the word out and to talk to people that you need to do whatever you can do to prevent. And that's just with any woman, you know, any time the subject comes up or anyone has the suspicion, get yourself to the doctor, have a mammogram, have yourself examined. Be sure. Don't think about it.

Similar to this awareness of breast cancer and the move from discussing it in whispered tones to more open dialogue about the disease, Tisha, whose mother had breast cancer, mentioned her friends' efforts to proactively raise the profile of breast cancer prevention in their community. "I'm in a sorority and we do functions and we do walks together for that," Tisha revealed. She also referred to a breast cancer education group her friends had formed to pass out pamphlets and materials at malls and health fairs. Several other women recalled breast cancer events and breast cancer awareness efforts, including Susan G. Komen events, pink ribbon magnets on cars, and a local television news anchor who survived breast cancer and tries to raise awareness in the community.

Answers to Research Question 2. The second research question asked about the individual, interpersonal and cultural factors that influence African-American women's beliefs about breast cancer prevention. It also asked what the women thought breast cancer means to

their communities and how members of their social sphere and community talk about breast cancer. The themes that emerged from the interviews did not answer the first sub question exhaustively because it seemed that despite some differences in the women's backgrounds, most held the view that breast cancer was closely tied to genes and that genes were uncontrollable. The other factor that may have influenced views about prevention, at least in terms of being diligent to adopt secondary prevention behaviors, was having a family history of breast cancer.

Answers to the sub questions regarding the communities' treatment of breast cancer varied. Some women cited "old" views of previous generations that believed cancer was to be dreaded, it was almost always a death sentence, and that people with the disease may have done something to cause them to develop it. More modern views recognized that technology and medicine had advanced to the point that cancer was often survivable. Women did not say that their communities held one or the other view exclusively. Instead, like many of the women interviewed expressed of their own views, the fear of cancer may be coupled with recognition of improved treatment opportunities.

Despite views that cancer is associated with negative outcomes, most of the women cited other health problems as being more dominant in their community. These women referred to perceptions of that high blood pressure, diabetes, and other diseases affected more people in the community, therefore these diseases may be higher priorities or at least more commonly talked about in the community.

Most women without family histories of the disease said they did not talk about breast cancer much in their social circles, mostly because they said they did not talk about things that were not affecting them personally. Women with family histories reported that they did talk about the disease with family members.

Prevention Information and Internet Beliefs

Women's perceived lack of need for breast cancer prevention information. The women mostly had not looked for primary breast cancer prevention information. This seemed to stem from the lack of perceived personal risk of the disease due to family histories free of breast cancer and the related belief that the disease is a genetic fate that cannot be prevented, only detected early through secondary prevention. Of the women with family histories of the disease, only two said they had sought information recently and neither had looked for primary prevention information.³ All of the women who had this family history expressed some beliefs that they remembered the information they had received around the time their loved one was being treated for breast cancer, and thus they did not feel the need to actively search for additional information. Among the women who did not have a family history of breast cancer, only one said she had proactively sought breast cancer information. She did so after a personal scare and said she did not look for prevention information at that point.

Given the rare event of women seeking out prevention information, the interviewed women were asked more general questions about health information-seeking. The majority opinion was that women would be unlikely to seek information about a health topic unless it was affecting the women personally or they had family members with the condition. This proximity to the disease concept answer, either in the form of a loved one's diagnosis or a personal experience with it, was common to both breast cancer information and general health topic and disease information-seeking prompts.

Just as it was uncommon among the interviewed women to seek information about preventing breast cancer, the women thought other women in their community also did not look

³ One wanted information about new technologies to detect tumors. The other needed some information for a class she was taking.

for such information. As Tisha put it, “I don’t know anybody who has looked up information for that particular disease, myself.” Mandy said, “It’s not a common thing. The women in my community, they aren’t going to get out and look for anything. If it comes up, it’ll be from them going to the doctor and the doctor, you know, telling them what to do.”

The two reasons women gave for why they might look for information about breast cancer prevention were a family member getting the disease or having a personal scare. Linda said she did not search for this information because it “never crossed my mind. I didn’t have it and no one close to me has it to make me want to be curious.” Ada said she would not look for information on a topic like breast cancer “unless it was something dealing with me.” And Joyce said, “Well, I just...I guess I don’t. If nobody is affected with it or if it’s not affecting me directly with it, or somebody I know, I just never thought to just look for it.” From the perspective of a woman whose family members were affected by the disease, Mandy surmised that most women do not seek this information because “because I don’t think they know the seriousness of breast cancer. I don’t think they’ve done the research on it unless it’s happened to them. I think that’s the reason why.”

Women were consistent with the theme of proximity to breast cancer when the question was rearranged to ask what would make them or other women want to find information about breast cancer. Whereas women said they had not looked for breast cancer or prevention information because the disease had not affected them, they replied to the question about what would make them or another women seek information by saying that a family member being diagnosed or the women themselves finding a lump or having a suspicious mammogram would cause them to learn more about breast cancer.

Tisha said a personal scare or a family member having breast cancer would cause a woman to look for more information about breast cancer. She said:

Maybe some people might just go on there just generally for information but that probably will be small, a small number. I would think people just pretty much go on there to learn about something that's happened to someone they care about or know about.

Joyce also said women would not look for this information unless it is "concerning them," referring to the women or their families. "But like if it's pertaining to my family, I will [go on the Internet] so I can try to get a better understanding of it." Ada also said that she would only look for this information if she experienced "someone else – someone close to me getting it. Like a mother, sister, close family." Similarly, Rachel said women would likely only look for breast cancer information if somebody in their family has had it. She said,

Maybe because it's hereditary, you know...in black people's communities, uh, they get more interested in stuff if they feel like – like I told you before like their aunt or their mother or their grandmother had it. That's when they get more concerned.

This theme of seeking disease information if a family member is diagnosed seemed to have two dimensions. One is that this information would help the women know how to help their loved ones. For example, Ada described how she sought information for her husband after he was diagnosed with cancer in order to find the best treatments available. Joyce said she would look for information about a condition affecting a family member in order to offer that person support and to be prepared for the treatment process,

Because I would want to know. I would want to know what other people are facing, you know. What I could do to help that person. You know, to talk to that person, to comfort that person, like, "Oh, it's going to be okay." You know, whether they're taking chemo, if it's going to make them sick, throw up, you know, lose their hair. Whatever. What I could do to help that person.

The other reason related to family members' diagnoses was the possibility that the women's own assessment of personal risk might increase when their relatives are stricken with the disease. Tisha put it like this:

Say a family member has had one of the diseases and they go – a lot of people I know – might have been a parent, see, that has had the disease or whatever, and then they go and do extensive research themselves because they want to find out ways to prevent it. Like if that parent had it and a couple of sisters or brothers had it, then we want to find out how to prevent it.

Breast cancer scare prompting information-seeking. The women mostly thought they would look for breast cancer information if (meaning after) they received that diagnosis. When asked why women might look for information about breast cancer, Linda said, “Yeah, because they have it. Because they got it.” Rachel thought she would only look for breast cancer information if she had tests that indicated she might have the disease. “First of all, like the only reason why I would look for that information is if I had like a positive mammogram or something.” Ada said she would not look for breast cancer information unless it affected her directly. In fact, Ada said that she was not prompted to learn more about the disease even when women close to her were diagnosed with it. “Um, unless I had a scare, I mean, unle—even when my friends and my mother-in-law had it, I didn’t try to go out and find any information. I didn’t go and try to find out...no, I didn’t.” She said her mother-in-law’s experience did not prompt information-seeking because the woman was not a blood relative, referring to the inherited gene association with risk.

Betty also surmised that a personal scare would make her look for breast cancer information, but unlike Ada, she would also look for information about diseases that affected other members of her family. She said:

You know, if somebody – if I went to the doctor and they said, ‘You have a nodule about this size,’ I would probably seek it out and you know go after all the information I could about it as it pertains to me and what is said about me or certainly my husband or somebody that I know.

Joan, whose family had been affected by breast cancer, thought other women would not be interested in learning more about the disease unless one of the two conditions of personal experience or a family member's diagnosis made the women curious:

Somebody – I'm going to be honest with you – either they have to be diagnosed or somebody they know or a family has to be diagnosed because a lot of times we don't really want to search out or find things until it actually happens or we know somebody that it happens to.

Another woman, Joan, who had a family history, said she sought information because she was "just curious," but not unlike the theme of looking for information after a family member's diagnosis, Joan said this search for knowledge was to see what detection technologies were available now versus when her sister had breast cancer seven or eight years earlier.

Three women associated the lack of perceived risk with the lack of information-seeking by tying their opinions back to my project's interviews. Most generally, Rachel said she thought a lack of knowledge about breast cancer would prevent women from seeking information. She said,

I think one reason why black women – most black women – don't know anything about breast cancer is because of denial and lack of information. Um, it's just uh, um, it's a lot of things in our community that we just don't know anything about. I don't know – some of us, a lot of us do want to know about breast cancer and some of us just don't care, but I do want to know about breast cancer because I want to know how to prevent it and uh how can I help someone else prevent it.

This seemingly paradoxical statement about lack of knowledge as a barrier to seeking information may be explained by community and cultural views of breast cancer, as well as the belief among the interviewed women that breast cancer risk relates to family history and therefore cannot be prevented.

Ada and Betty made statements that may support this idea that a lack of knowledge about breast cancer – its causes, risk factors, prevention, and survival rate – may make women not want to know about breast cancer or not feel vulnerable enough to the disease, based on lack of

family history, to look for information. Ada suggested that participating in the interview about breast cancer was leading her to think more about the disease and her risk. These thoughts might make her want to learn more about the disease and prevention so she could avoid it.

I would try to find out what I need to do so I wouldn't be in that...counted in that theory. I would want, you know, to do better. 'Cause like I said, I didn't know that it was something you can do to prevent it; I just thought it was hereditary so that would be inform—a lot of information for me because then I'd find out that it's not.

Betty predicted that other women interviewed might be prompted to learn more about breast cancer prevention after speaking with me about it.

I mean, some people – you might find that you interview, that as you begin to ask questions about it, it will kind of plant questions in their minds to make them want to go and you know just simply ask – like I said, I use Yahoo – to say “Okay, I'm an African-American women, 56 years old, with da-da-da-da-da-da-da, certain weight, what I eat, da-da-da-da-da...What are my chances?” You know, “What are the risk factors that I should be looking for and um, what do I need to do to best take care of myself?”

She said that even women who had not been interviewed might sometimes seek information after viewing a billboard about breast cancer awareness or a TV program about the disease. Melissa also said women might seek information if “they heard something on the news.” However, the fact that some interviewed women said they probably had seen news stories about breast cancer but had not actively sought information after that suggests Melissa and Betty's theory did not reflect the other women in the qualitative study.

Answers to Research Question 3. This research question asked what emphasis women placed on personal, proactive breast cancer prevention information-seeking. The answer was that most women had not searched for this information; therefore little emphasis seemed to be placed on proactive breast cancer prevention information-seeking.

Internet non-use related to physical access. Those interviewed women who were not regular Internet users gave logistics-centered reasons for their non-use, including lack of physical access and time and low Internet skills, as opposed to beliefs about the usefulness or

trustworthiness of the tool's information. The women who used the Internet had positive views about the medium. They described multiple anticipated tasks for which they use the Internet, such as for e-mail communication and information-seeking. This subgroup of interviewed women was very good at describing these specific functions they used the Internet for, but only a few women interpreted the questions about the medium's role outside of concrete examples of its use. The women spoke of the Internet allowing people to do some of the same tasks they have always done (pay bills, renew library books, find movie times, or research medications), but quicker, easier and more privately. These women's view of the Internet's role in their communities was that it generally mimicked the role in the interviewees' lives. They thought their friends and neighbors likely used the Internet for purposes similar to their own.

The women described the Internet in very simple terms. For the women who used the Internet a great deal, the medium was a tool to do many things at work and at home. They appreciated its benefits more than they were frustrated by its outcomes. In fact, most of the statements by these women were very positive. One of the women waxed eloquent about the Internet's impact on her life by describing how things were done before the Internet came along: "It makes information a whole lot more accessible to people because, um, I'm just at a unique age where I can remember life without computers and Internet and where you had to dig a lot deeper and a lot harder in order to find." The other Internet users described what they used the medium for and what they liked about it; the latter issue will be described in detail in the discussion of subsequent research questions. In no case did the women give abstract answers about the Internet's role in a larger social context, such as acknowledging the impact of a digital divide on solidifying class distinctions.

For the women who did not use the Internet, or did not use it often, the primary barriers were time and access. These women did not seem to have negative opinions about the Internet; rather their needs and life priorities did not include the medium. However, even one woman who was not very familiar with the Internet had a computer with access at her home because she viewed it as integral to her children's futures. This woman, Linda, explained that her employer at her housekeeping job (one of three jobs she had) had given her a computer and she paid for Internet access to help her children do schoolwork without having to go to the library. "So I'd never let my computer Internet go out. It cost more, a lot of money, but I just keep it going for the kids. They're in school," she said.

The least frequent Internet users gave answers indicating that their non-use was not related to suspicions of the Internet or beliefs that it was a bad tool. Mandy said, simply, "I don't have one. I don't have access to the Internet. I don't even own a computer." After several probes, this woman volunteered little about why she did not use the Internet, saying only, "It's not that I don't like it. I just don't have time. I be busy all the time. I just be busy all the time." But this woman did say she had asked other friends and family members to look for information on the Internet for her, indicating that she saw some value in the medium.

Linda, the woman who wanted the Internet for her children, said she used it "sometimes. I don't know much about it. No more than [laughs] playing games," suggesting a lack of familiarity with the medium. She also cited the three jobs she worked and the lack of time for things like the Internet. "People do use the Internet more. Like I said, you have some who are on it every day, all day. But I'm not. It depends on your job."

When asked what role the Internet plays in their lives, the women's answers were very simple and to the point. "It's an everyday function," Joan said. Melissa and Tisha both said the

Internet plays “a major role” in their lives, as they use the medium every day and for multiple communication and information purposes. Betty and Ada also described a range of tasks for which they use the medium. Betty laughed, called it the “information highway,” and said it had become part of her life. Ada summed up the Internet’s purpose as a user-driven tool as allowing one to “find out different things that you want to find out.”

Joyce and Linda both described the Internet as being something their children were learning or had learned about in school and the influence of their children’s Internet use on the women’s interpretation of the medium’s value. Linda said,

‘Cause you got information right at hand. You can key it in. Once you get the use of it, ‘cause my kids download and burn everything, set up the computer. I don’t know how to do none of that. I let my 16-year-old do all of that. Because they’re taking it at school. So that’s how. My 12-year-old, she knows because she take it at school. She goes to [high school name]. So they know.

And Joyce associated her own use of the Internet as opposed to its non-use by other women in her community as being related to having children.

I don’t think, well, with me being the age that I am, well, a lot of people, they don’t have kids growing up, and you know, using the Internet or computers and stuff; I don’t think they really just go on the computer or Internet. I just have two grown kids so I made sure I had a computer in my house when my kids were growing up, so I’m used to being on a computer. A lot of people don’t work with computers, you know. If they work in a coal mine or plants or something like that, they don’t have a computer that they’re working on with their jobs and like doing Internet stuff so I don’t really think they’re into it.

Joyce’s view of why some women do not use the Internet segues into the women’s answers to questions about the Internet’s role in their community. Again, none of the women answered in analytical terms, such as the impact of the Digital Divide, the need for Internet skills for success in some careers, or cultural beliefs about the Internet’s utility. Instead the women spoke more concretely about how people in their social circles used the tool. Melissa summarized a common answer that she thought her community’s use of the Internet was similar to her own. “I think, for

the most part, my community uses the Internet, um, for the same purposes that I use it – for checking email and just finding information, for just news, current events.”

With the exception of Mandy, who reported to know only one other person in her community who used the Internet, most of the women said they thought use was very common among their friends, family members and neighbors. Some women’s conjectures indicated that older people and those without children living at home might be less likely to use the Internet; however, women’s answers to the questions about the Internet’s role in their communities indicated that they believed the medium had largely diffused to reach the older and childless, too.

Tisha said,

Um, a lot of older people on the Internet. Um, you know, young, old. Uh, middle-aged. Um, everybody’s on it. They’re looking for a recipe, they’re looking for or trying to find information about how to buy tires, or something like that. They look on the Internet pretty frequently now, a lot of people in my neighborhood, old and young.

Betty made similar comments, suggesting that the myriad features of the Internet made it a useful tool for a range of people. Joan echoed this sentiment, responding to the question about what the Internet means to her community by saying:

I mean, it plays a broad role because there’s so much you can do with it. I mean, there is so much that you can do on the Internet. And I think it plays a very big role for those who are willing to go out there and access it. Because you can find any information, anything you want to know is out there.

Answers to Research Question 4. This research question asked what women thought about the Internet and how they described the Internet’s role or importance in their social setting or community. The women who used the Internet said they thought it was a useful tool for a variety of tasks. Very few of the women cited negative aspects of Internet use. Even the women who did not use the Internet much did not express negative beliefs about the Internet. Those women merely cited lack of time, access, and skills as reasons why they did not use the medium. Although the women did not speak abstractly about the positive and negative impacts of the

Internet on their community, such as the advantages it might offer users in the workforce or the disadvantages associated with the Digital Divide, the women suggested that other people in their communities likely used the Internet in ways similar to the women's own online habits and purposes for use.

A belief that the Internet would be a good source of info about breast cancer, if a woman wanted that information. Most of the interviewed women had not looked for breast cancer information in the past. Those who did were prompted by personal or family events, rather than simple curiosity or an interest in primary prevention. The women thought that the Internet would be a good source of breast cancer information if a woman had a reason to look for it. In other words, if a woman wanted to learn more about the disease, the Internet would be a good tool for her search. However, the interviewees' beliefs that women are unlikely to seek out information about a condition that is not affecting them revealed that the Internet would not be a good stand-alone primary prevention intervention because women without family histories of the disease probably would not use it.

Interviewed women said the Internet would be a good tool for finding information about breast cancer, but a woman would be unlikely to look for it unless it was affecting her. Joyce said, "The best way to find out is through the doctors or the Internet. And if you don't have [breast cancer], you wouldn't just, 'Oh, let me just go to the doctor and let him tell me about breast cancer.'" Betty said she knew of some women who had used the Internet for breast cancer research and said they "found some very good information concerning exactly what they needed for themselves," so she would be likely to use the medium if she needed information about the disease. Ada also spoke hypothetically that if she wanted to learn more about breast cancer, she would turn to the Internet. "I mean, I think it's good. The information, I mean," she said, and

went on suggest that she imagined the Susan G. Komen Web site probably had some useful information about the disease.

In summary, the women thought, based on their experiences looking for other information online, that the Internet would probably be a good source of information if a woman wanted to look for information but might not be a good method to share prevention information with women who were not actively trying to learn about the disease. Tisha explained,

...you can pass out pamphlets in the mall and [women] might look at them. They might throw them away. But you just pass it to each woman. But if it's on the Internet, more than likely somebody's going to actually go and take an interest and look it up themselves, because the Internet doesn't just pop up. Like a pamphlet, somebody just gives it to you. You really have to go research and you look it up yourself [on the Internet].

Another theme was a preference for doctors' advice. Mandy said, "The women in my community, they aren't going to get out and look for anything. If it comes up, it'll be from them going to the doctor and the doctor, you know, telling them what to do." Linda also said that she might listen to what a friend said about a disease, or consider the information from a Web site, but normally she would go to the doctor to learn about a health condition. The things Melissa said she might use the Internet to find out about are health questions that she did not feel comfortable asking her doctor about.

Tisha said she might look on the Internet, "but the majority of the time, if it's something I want to ask, I'd wait until I go to the doctor and I'd ask them, per se, and just go from there." She continued to describe some concern over the quality of information on the Internet and how well that information applied to her situation and her ideals,

[the Internet] has some good information on it but if it's...like if I had a rare cancer or something like that...if I looked it up on the Internet, a lot of stuff that might pop up later might say, "You need to – you might eat this certain type of grass that might help you." Or over here might say, "You take this certain type of drug." But of course, you know you got the natural healing and the medicine healing, you know. And depending on what type of, uh, I guess I'd say what kind of background you come from, what you do, which one are you going to go with? So, I would ask the doctor instead.

Answers to Research Question 5. This research questioned asked what African-American women think about the Internet as a source of breast cancer information. It also asked how women who use the Internet for breast cancer information describe their experience. Few of the women had actively searched for breast cancer information in the past. However, most thought they would use the Internet for that information, if they perceived a need for breast cancer information in the future. The women who had searched for breast cancer information described successful attempts at getting answers to their questions.

Health information-seeking on the Internet is a common activity. Active breast cancer information-seeking using any medium was uncommon among the women interviewed, but the women did report use of the Internet for other health information-seeking. Women who did not have family histories of the disease indicated their non-information-seeking behavior was related to factors other than the medium, such as low knowledge of breast cancer and low perceived risk of the disease, rather than feelings about the Internet as a breast cancer information source. Women who did have a family history of breast cancer said they had looked for information on the disease when their relatives were diagnosed and felt confident in their knowledge of the disease and prevention. Therefore, a simple answer to the question is that no features or characteristics of the Internet were cited as enhancing or deterring these women's breast cancer information-seeking. This is not to say that certain features or characteristics would not be facilitators or barriers to seeking information; rather the question cannot be answered with the available interview data. Among the women who did not use the Internet for health information-seeking, the primary obstacles were lack of time, lack of access, or lack of computer skills, so it is technically possible that associated characteristics such as cost, infrastructure, and complexity of the Internet acted as an obstacle to breast cancer information-seeking. However,

the women in this category did not express that they had – in the past or currently – wished to use the medium for breast cancer information-seeking but were deterred by these characteristics.

Given this finding, the interview questions about breast cancer information-seeking were re-conceptualized to describe more generally women's impressions of the Internet's features for finding health information. Also, women were asked a hypothetical question about what Web site characteristics they would prefer if they sought breast cancer information. The three main features and characteristics women cited as enhancing their health information-seeking experiences were convenience, the wealth of available information, and the simplicity of searches.

Convenience of searches. For women with computers and Internet connections at home, the convenience of using the medium at any time was very appealing. Ada explained the convenience by comparing the tool's use to the methods people would have used before the Internet: "Instead of going to the library and you have to go through all these books, um, you can just put in one thing and get, you know, all kinds of different information." Even Linda, who said she did not know much about the Internet, said it was important to her to have a computer with Internet access at home to keep her children from having to go back and forth to the library. "Cause you got information right at hand. You can key it in," Linda said.

It's a good feeling because you don't have to go to the public library for one. And you don't have to go check out a book, and that's my main source why I got the computer, because I didn't realize that my kids was going to the library just to use the computer. Once we got it, we saved a lot of time.

The library replacement notion came up with Tisha and Melissa, too. Tisha said:

You can find a lot of information quick. You don't have to leave your home. Say, you don't have to go to um, go to the library and pull up a book and then go through the different topics to find exactly what you're looking for. The Internet just kind of labels topics and then just say, "okay, boom," and it gives you just kind of a brief summary under it so you can just say, "yeah, that's what I want." And if it's not what you want, you can

just come out of there and look for something else. So it's better than say going to the library and they say you can't get more than five books at a time, something like that.

And Melissa said:

It's easily accessible, more so than the library because you don't have to drive down to the library. And it's just more time consuming to go so somewhere else versus using the Internet because all you have to do is turn the computer on and, you know, you've got information at your hands, in an instant.

The issue of privacy, which is often cited in the literature as a reason why people like to do health searches at home, only came up in those specific terms in the interview with Tisha. She said:

Some people do it in the privacy of their home. You know, they won't feel like, "Somebody sees me going out here," if it's something personal going on with them. I know people that are really like, "I don't really want nobody to know about that," you know. Some people are, some people don't care. But it's good if they can have the access in their home, and you know, if they couldn't get out of the house they could look up stuff and see how could they take care of themselves.

This issue may go back to the previously discussed idea that health and especially breast cancer are very private matters for many people, and they may be more likely to look for information about health concerns when they believe they can do so without anyone finding out about it.

Simplicity of searches and the wealth of information. These two themes are discussed together because so many of the women's quotes regarding what they liked about the Internet mentioned these two concepts in one sentence. For example, Betty said about the medium, "It's pretty easy – it's usually pretty easy, I'll say, to find what you're looking for and it gives you a lot of choices and a lot of different areas that you can look into, uh in order to find that answer." Similarly, Joan noted that positive characteristics of the Internet include "the access and the ease of finding the information that you're looking for and the broad scope of information that's out there."

The simplicity of searching for online health information involved two related concepts: the search engine technology was easy to use, requiring just a few keywords and mouse clicks, and this method resulted in efficient, even intuitive, answers to the women's questions. The distinction is largely a matter of steps in the process. Tisha described the first aspect of the simple search – the ability to find information without having to type in a specific Web address or uniform resource locator (URL). She said:

I like Google, I mean, because it's easy to do. Because pretty much if you type in the topic under Google, it comes up with whatever it is you're looking for. If you type in "www-dot-something" in the World Wide Web, it's gonna take forever, and you're going to have a bunch of nonchalant uh, no nonsense, you know, it's not going to be direct. It seems like if you go to Google, it's direct.

Rachel said the information just "pops up" after she enters keywords for a topic. "I would just go into address bar and just type in 'lymphedema,' or 'newest research on lymphedema' and that's it," she said, describing how she would search for information on that condition and what her expectations would be for that process. Joan called the Google search process "user-friendly."

The second aspect is that the keyword entry method is effective; it locates the information the women seek and presents the information in a way that enables them to find answers to their questions easily, either on the search engine page hits list or on the actual Web pages generated by the search. Joan said, "I mean, there's so much – there are so many sources, especially when you Google stuff. When you put in a word and you have all of these sources that come up and you know you get to see it from different aspects or different views."

Betty referred to this presentation and organization of Web page content as the useful way the medium "categorizes things" so that a person can move from topic to topic. She said, "...just follow the line. Follow the yellow brick road through it and see where it leads" in terms of topics and information that can be learned.

Tisha also explained this concept – that of being able to quickly see if a Web page has the information she wanted:

The Internet just kind of labels topics and then just say, “okay, boom,” and it gives you just kind of a brief summary under it so you can just say, “Yeah, that’s what I want.” And if it’s not what you want, you can just come out of there and look for something else.

Many of the women liked being able to scan a Web page quickly and see, due to the way information is presented in headings and subheadings, if the information will be useful to them.

Joyce said:

It tells you everything. It tells you what – I mean, if you’re looking for just – like you said, breast cancer – it tells you what causes it, what it is, whether it’s a mass, what to look for, what procedures. It breaks it down, step-by-step. If you have to have surgery, what type of surgery it is, what they do in the surgery. It tells you about the chemo. It just breaks everything down, step by step.

They saw this as being a major advantage over more traditional forms of print material research.

Presumably, it is an advantage over television and radio information sources that do not allow for user control, although neither of these media was mentioned. Two of the women did say that the Internet’s health information was more useful to them than brochures and information in doctors’ offices when the women wanted answers to specific questions. Joan said:

Because it’s easier to access, it’s easier to find. For me it is. I mean, because you can’t just walk into a health facility, I mean, they don’t have pamphlets on everything. And especially their technology – it’s brief, and I guess I wanted a little more in depth knowledge.

When Joyce described a recent online health search, I asked her why she had chosen the Internet for her search and she said, “There just wasn’t a lot of information in the doctor’s office” about the rare condition she wanted to learn more about.

Another key theme was the wealth of information about health topics that one can find online. For instance, Betty said, “And then, I cannot emphasize enough the information that’s available on it, you know, and how easy it is to attain that information.” Joan referred to the

“broad scope” of available information. She said, “You can find any information; anything you want to know is out there.”

Answer to Research Question 6. This question asked about the features or characteristics of the Internet that enhance or deter women’s experiences seeking breast cancer information. Due to the low reported cases of breast cancer information-seeking, the specific question could not be answered. Overall, women who used the Internet for information about other health topics cited the ease of searches, the way Web sites organize content to make answers to questions easy to find, the wealth of available topics, and the convenience of searching at home or other place at any time as things they like. Limitations or drawbacks included content quality and accuracy issues and a preference for communicating with doctors about health questions.

Summary of women’s beliefs about online breast cancer information-seeking.

Reported reasons for not using the Internet in general were related to lack of physical access, Internet skills, and time for online activities, not beliefs about the medium. Reasons for not using the Internet to find breast cancer information were related to perceived personal risk of the disease or family experiences with breast cancer, not beliefs about the Internet as a source of that information. In fact, the women who had low perceived risks reported that they had not actively sought information about the disease from any source.

Among women without breast cancer histories, the interview participants’ beliefs that they were not at personal risk for breast cancer seemed more responsible for their lack of information-seeking behavior than any belief about the Internet as a source of this information. This association has already been discussed. With the exception of the low Internet users, the women in this particular category reported to have sought online information about other health conditions, indicating that they believed the medium was a useful source. In addition, some of

the themes presented earlier in this chapter show that women believed the Internet would be a good source of information if they wanted that information. However, with their lack of perceived personal risk, the women did not think about looking for this information.

The women who did have family histories of breast cancer said they believed they were at risk for the disease, but only one said she had looked up breast cancer information recently (the secondary prevention screening information sought by Joan). The women did not report a belief that the Internet was a bad source of information about breast cancer. In both groups – women with and without family histories – the interviewed women had in common a belief that they did not need more information about breast cancer. Women with histories believed they already had the information they needed; women without histories did not express the vulnerability to the disease that might prompt them to want information.

Answers to Research Question 7. The final research question asked if among members of these two groups – African-American women with breast cancer family histories and those without them – their reasons for using or not using the Internet were more related to their beliefs about breast cancer or to their beliefs about the Internet. The answer seems to be that beliefs about breast cancer influence their beliefs about the need to seek prevention information.

However, this answer should not imply that women who believed themselves to be at risk would automatically be prompted by this belief to seek prevention information. While women who did not have a family history of breast cancer said they would not be likely to search for this information unless they had a personal scare or a family member was diagnosed with the cancer, women with the family history might not search for information if they believed they already knew everything they needed to know about breast cancer. Another clue that beliefs about breast cancer influence decisions to seek more than beliefs about the Internet is the women's comments

that if they wanted more information about breast cancer and prevention, many if not most of the women with physical access to the Internet would use the medium for this purpose.

CHAPTER 5 SURVEY METHODS

Chapter 5 will describe the role of the survey in this study, how the survey questions were developed, the sampling method used, and data analyses performed. The chapter will also show how the literature and need for further exploration of research questions contributed to specific questions on the instrument.

Role of the Survey in the Study

After the interviews were analyzed, they contributed to the development of a questionnaire that further explored emergent themes. Chapter 3 explained, in greater detail, the general advantages of using two different methods within one study. The role of the second method in this study was to complement the findings from the interviews. In this case, the word “complement” refers to following up on the specific themes that developed in the interviews as well as examining some variables and relationships between variables that the interviews were not equipped to examine. An example of the latter is exploring the role of age, income, and education level on beliefs about breast cancer prevention. Statistical analyses of these reported variables in relation to answers to questions about beliefs and Internet use allowed the researcher to see if correlations exist.

Advantages and disadvantages of survey methods. Surveys’ traditional purpose is to find out something about a large population by using statistics and sampling techniques to extrapolate findings from a small, representative group of people. The interest is in seeing how certain traits are distributed in the sample and, by extrapolation, in the larger population the sample is thought to represent (Babbie, 1990). This emphasis on counting cases and using statistics to make interpretations about the sample and projections about the population it represents places survey methods within the quantitative paradigm. However, as Chapter 3’s

section about mixed methods explained, surveys can still be used to complement qualitative research by further exploring the themes that emerged from interviews. The difference is one of interpretation; this present study made no attempt to claim that the findings from either phase of the research were representative of the larger population. While some surveys' purposes are to explain relationships, this survey only described and explored the topic in more detail.

Surveys can be conducted in a variety of ways using many formats; however, they all consist of sampling, question design, and data collection (Fowler, 2002). Quantitative research designs usually use probability sampling to increase likelihood that the randomly selected sample represents the population under study and statistically accounts for chance. This sampling technique and an appropriate sample size allow the data to be explored with advanced statistical analyses that can point to significant and sometimes causal relationships between variables. While quantitative-only studies use large, probability sampling, qualitative-focused projects may use smaller, purposively selected samples "so as to select only those cases that might best illuminate and test the hypothesis of the research team" (Kemper, et al., 2003, p. 279).

Although surveys offered this study the advantage of being able to explore themes emerging from the qualitative research phase using well-crafted questions, survey methods have some drawbacks. Most of the disadvantages reflect survey research's roots in the quantitative objective paradigm as they strive for some clinical, uniform conditions and control over the study design. Included are selection biases in respondents, low response rates, responders' misinterpretation of questions, costs associated with administering the surveys, and the possibility of people providing socially desirable answers to questions as opposed to answers that reflect their real opinions (Fowler, 2002, p. 98). Some of these disadvantages, such as selection

bias, are difficult to overcome, while others, such as the tendency of respondents to give socially desirable answers, can be mitigated through good instrument design.

The person (respondent) is the unit of analysis in this study. The population in this study was African-American women aged 35-65, without breast cancer histories. These race, gender, age and disease history variables represent the parameters.

The survey used in this study was written, self-administered and structured, meaning that the questionnaire had preset answer options as opposed to blanks for people to write in their own answers to every question. The survey was paper-based, as opposed to online, because the research questions sought feedback from some women who do not use the Internet, and an instrument the participants read and completed themselves. Self-administered surveys have the advantages of allowing people to answer sensitive questions without having to share that information directly with an interviewer and letting the researcher ask many related questions about themes (Fowler, 2002). However, the researcher recognized that vision and literacy issues might have precluded some participants with useful thoughts to share from completing the written form.

Disadvantages specific to self-administered surveys include the lack of control over who answers the questions and the quality of those answers, the possibility that literacy issues may limit responses, and the limited practicality of including open-ended questions (Fowler, 2002). The survey was administered in some group settings. Although group settings may not be appropriate for selecting probabilistic samples, they offer logistical advantages to the researcher, including opportunities for her or a representative to explain the study to the group, lower costs, and good cooperation rates (Fowler, 2002; Johnson & Turner, 2003). Group-administered surveys were appropriate for the present study because of the need to reach a minority within a

minority, meaning the eligible participants represent a smaller percent of people who are already part of a racial minority. By identifying existing social groups of African-American women in the study's age range, such as religious groups and community organizations, the researcher increased the number of survey respondents fitting the study's parameters.

Survey Development

The survey was developed after analysis of the interviews. Themes and subthemes that emerged in the interview stage inspired the survey's questions and design. Not every theme or subtheme was addressed in the survey, as some would require asking many questions to explore the concepts. Themes that were incorporated included a woman's proximity to breast cancer influencing her beliefs about the disease, which was probed in the survey by asking women if they had first degree relatives with breast cancer and then comparing answers to other questions according to whether the respondents had a family history.

The theme of women emphasizing secondary prevention prompted the researcher to include items about mammography where she originally sought to focus on primary prevention. The theme about women's lack of knowledge about breast cancer was partially explored with a question asking women what they thought were risk factors for the disease. An interview finding that women tended to talk about breast cancer more if they had a family member who had experienced the disease prompted a question asking women if they had talked to another woman about breast cancer. To explore the conditional part of the theme – that women with family members who had breast cancer might be more likely to talk about the disease – the question asking women if a female relative had had breast cancer was used with the question about breast cancer conversations.

The theme of community disease priority relating to observing how common the problem is in the community was not explored in those exact terms, because that would have been

complicated in this survey; rather the researcher tried to see if the same other diseases mentioned in the interviews were cited by the surveyed women as community priorities. The theme that Internet non-use related to lack of physical access to the Internet was incorporated into several survey questions, most notably in a question asking women who did not use the Internet reasons for their non-use, with a list of choices that included physical access as well as belief-based reasons.

The theme about women's perceived lack of need for breast cancer prevention information was addressed in the survey by asking women if they had looked for prevention information, results of which might imply need (although it is fully understood that perceived need does not always translate to behavior). A theme that women were prompted to look for breast cancer information after experiencing a positive mammogram or having some other personal scare was addressed by asking women who had sought breast cancer information for the reasons why they searched for this information. Answer options included a "personal scare."

A final theme – that the Internet would be a good source of information about breast cancer, if women wanted that information – was incorporated into the survey with questions that asked women what Internet features and characteristics would prompt them to, or not to, use the Internet for breast cancer information, if they needed that information. Also, a belief question asked women how likely they would be to use the Internet to seek breast cancer information.

Surveys were anonymous and confidential. Information asked included basic demographics such as age, education level, relationship status, number of children, family history of breast cancer, and income level (see Appendix D). Other questions included beliefs about risk factors for breast cancer, the time a woman spends online in a typical week, and her beliefs about breast cancer prevention. Every person's questionnaire had the same questions, but

the instrument instructed some participants not to complete all the questions. For example, the questionnaire had items asking if a woman might look for information about breast cancer on the Internet. If she answered that she would do this, another question asked her what Internet features might make her want to use this source. Women who had answered “no” to the question about using the Internet for prevention information were directed to check reasons why they would not do so. The survey protocol and questionnaire form were submitted to the University of Florida’s Institutional Review Board for approval.

The interviews, the literature described in Chapter 2, and the research questions contributed to the survey instrument’s development. In its role as complement to the interviews, the survey explored themes and subthemes that emerged from the interviews. In addition to this interpretation of complementing the interviews, the surveys were able to pose questions in a different, closed-ended format that helped answer research questions the interviews could not explore very thoroughly. A prime example of the latter is the research question that asked what individual factors might influence women’s breast cancer prevention information-seeking. Although the interviews suggested some factors, the surveys allowed the researcher to compare women’s self-reported information-seeking with their demographic information, family history, and other variables.

One very important point that will be discussed in the limitations section of Chapter 7 is that the desire to measure many different themes and concepts in a single survey, yet not make the survey so long that it discouraged participation, was an important consideration. Women who reviewed the survey before it was finalized suggested that they would be unlikely to complete the questionnaire if any more questions were added to the instrument. Because this study is exploratory, the researcher opted for a cursory overview of many major themes instead of an in-

depth examination of only a few themes. As a result, many themes were explored with only one or two questions. Another important point to note is that not every qualitative theme was explored. The reason for this is that the survey had limited space to explore questions, and some themes were considered too difficult to examine with only a few questions or they were deemed less relevant to the research questions. In some cases, a subtheme of that theme was explored on the survey. One example of such a case was the interview theme of openness and advocacy about breast cancer. While this was an important finding, it would have been difficult to assess with a few questions. Ultimately, the subtheme about women's discussions of breast cancer relating to personal or family experiences with the disease was included because it was more directly related to the differences in beliefs and behavior by women who do and do not have family histories of the disease.

This discussion of question development will not describe the survey questions in their chronological order because that order was influenced by question format (questions were grouped by answer format in an effort to simplify the instrument for respondents); rather it will describe themes and the questions that relate to each theme.

Questionnaire Format and Pretest

Format and scale decisions, such as whether the questionnaire used Likert-scale or agree-disagree items, were made based on existing instruments in the literature and the format the researcher thought would provide the best design for each question. Survey literature provided some general guidelines for question design that informed the instrument development. Fowler (2002) advises survey researchers to use little variation in answer option formats to limit confusion. In other words, the survey avoided excessive switching back and forth between different category scales, agree-disagree questions, and multiple choice answer items. The

instrument made efforts to use common, well-defined, familiar words instead of terms that might be too ambiguous and to avoid asking multiple questions within one question.

The questionnaire was reviewed by ten white and African-American women in the study's age range before it was widely administered, in order to identify and reduce potential for problems. The reviewers were recruited from among key informants and other contacts the researcher used to recruit women for interviews. The reviewers were not provided an incentive to participate. They examined the instrument and made comments, when necessary, about question wording and questionnaire length. Comments were used to revise the instrument to its final form.

Survey Questions

The survey included general questions that were useful for comparing women's characteristics with their beliefs. The instrument also included questions that were associated with the themes and subthemes from the interviews. This subsection describes those questions and the reasons they were used in the survey. A final category of questions was summary belief questions assessed with Likert-scale items. Those Likert items will be discussed first as potential scales together and then as individual questions falling under themes.

The survey included nine Likert-scale belief questions that fell into the general categories of Prevention Benefits Beliefs, Personal Risk Beliefs, Fear Beliefs, and Internet Efficacy Beliefs, with the latter referring to a woman's belief about how well she could find information about breast cancer on the Internet if she wanted that information. These four categories are not actual themes from the interviews; rather they related to the categories of an existing scale instrument that was found to have relevance to the interview results. Individual survey questions came from Champion and colleagues' (2008) scales for measuring mammography and breast cancer beliefs in African-American women, based on the Health Belief Model. After the theory emerged from the qualitative portion of the study and revealed similarities to components in the Health Belief

Model, the researcher decided to include relevant scale items in the present survey. In this way, the interview themes themselves are not reflected by these categories; rather the overall theory emerging from the interviews prompted the items' inclusion in the survey.

Champion and colleagues' scales included questions categorized under susceptibility to breast cancer, benefits of mammography, barriers to mammograms, self-efficacy to get mammograms, and fear of cancer. This paper presents slightly different category terms to reflect the language used in the current study: perceived risk beliefs correspond to the scales' susceptibility and was changed because interviewed women used the word "risk"; prevention beliefs replaced the scales' benefits category to reflect that prevention in this study was not limited to mammography and because the interviews revealed few primary prevention behaviors for the women to assess benefit for; and fear beliefs corresponded to the scales' barriers category.

The current project's emphasis on primary prevention limited the utility of many of these questions about mammography. Due to relevancy issues and the general exploratory – as opposed to explanatory – focus of this project as well as the inability to cover the scales' more than 40 items about mammography beliefs in addition to questions about health and breast cancer information-seeking in a single survey design, only a few of the scale items for susceptibility, barriers, fears, and benefits were included. The items about self-efficacy to get a mammogram were rephrased with terms reflecting women's perceived ability to find breast cancer information on the Internet, which was more appropriate to this study. First, for the perceived risk beliefs, the following two mammography scale items were modified: "How likely is it that 'I will get breast cancer during my lifetime'?" and "'Compared to other women my age,' would you say your chances of getting breast cancer are higher or lower?" These questions

became the following Likert-scale agreement questions, with strongly agree, agree, disagree, strongly disagree, and no opinion as answer options: “I will get breast cancer during my lifetime,” and “Compared to other women my age, my chances of getting breast cancer are higher.”¹

The prevention beliefs items from Champion and colleagues’ (2008) scales used in the study were the following: “If breast cancer was found early, how likely is it that the cancer could be successfully treated?” and “Having a mammogram will decrease my chances of dying from breast cancer.” These items were reworded into statements with which the women would agree or disagree. In order to include an items related to primary prevention, one item not in the scales was included. It said, “I can do something to keep from getting breast cancer.”

The existing scales included a fear category, but those items were not explored here. Possibly creating confusion, the present study used two barrier category items that related to fear and recategorized these two items as fear beliefs. One survey item was derived from the scale item, “How likely is it that ‘The treatment I would get for breast cancer would be worse than the cancer itself?’” Another survey item rephrased the scale item, “How likely is it that ‘Being afraid of finding a breast lump would keep me from having a mammogram’”? into a prevention information-seeking behavior, worded in the following way: “Being afraid of breast cancer would keep me from looking for information about preventing breast cancer.”

The scale items for self efficacy involved perceived ability to perform tasks related to secondary prevention. Due to the study’s focus on prevention information-seeking behaviors instead of prevention screening behaviors, no scale items were relevant. Nevertheless, the language of one scale item formed the foundation of one survey item. That scale item was “I can

¹ The *no opinion* answers were not used in ordinal measurements in this survey because they did not represent a measurable degree of agreement.

find a place to get a mammogram (or know where to go to get a mammogram),” and the resulting survey item was “I believe I could find information about breast cancer prevention on the Internet easily.” No other similar items were found among the scale items. In effort to find another item related to using the Internet for breast cancer prevention information, the researcher created the following question: “If I wanted to find out what I could do to prevent breast cancer, I would use the Internet for that.”

These scale items’ use in this study was not to validate the items. In fact, the items’ formats and measurements differ in the original scale and the survey. The purpose was to take phrasing from items in the literature that reflected scholars’ testing, consideration for theory, and tailoring to African-American women. Given the exploratory nature of this survey, the use of single questions in this manner was appropriate.

The researcher first attempted to use the nine items to create four scales within the categories of prevention beliefs, personal risk beliefs, fear beliefs, and Internet efficacy beliefs, however each scale included two to three items each, resulting in a small number of items. Reliability analyses revealed poor internal consistency for all of these scales, with Cronbach alpha coefficients of .55 for Internet efficacy, .55 for risk, .49 for prevention, and .27 for fear. The mean inter-item correlation values were also too low for all four scales to be considered useful for measuring the belief concepts together. Therefore, the questions intended for use in constructing scales were used separately, for exploratory purposes, to compare with other variables including survey respondents’ Internet use and breast cancer family history.

General Questions

Demographic questions as well as some questions that provided helpful background information fell into the general questions category. The former should be clear from the description below. However, the latter – the post-analysis questions – require more explanation.

Health information-seeking was not a theme or subtheme; it was an overarching behavior guiding this research. Therefore, questions related to women's health information-seeking behavior were included. Similarly, women in the interviews and in the literature cited in Chapter 2 referred to some beliefs they had about the Internet, such as that it was easy to use or that it might not have trustworthy information. Those remarks were not full themes, but they were important details for understanding women's beliefs about the Internet; thus they were included in the survey.

Demographic questions. Useful surveys about health and Internet use require a significant number of items about respondent demographics. In an effort to understand potential factors involved in Internet use, researchers include questions about income, education level, and age, because these variables are, to some extent, influencers of Internet use. This study's survey included these demographic questions, plus marital or relationship status, and whether or not the woman had medical insurance. Age was also used to assess if the woman fit the study's age criteria – being between ages 35 and 65. A question about whether or not the woman had ever had breast cancer also served this purpose of eliminating women outside of the study's parameters. Another question asked women if they had ever had any form of cancer; however that question was not used for analyses because only three women marked that they had had cancer in the past.

One of the major questions asked was about the women's family history of breast cancer. Survey respondents were asked to check if they had a mother, grandmother, sister, aunt or cousin, or close friend with breast cancer. The close friend selections were not analyzed because they were not found in the interviews to affect women's personal perceived risks of breast cancer. Aunts and cousins also were not considered to reflect a "family history" of breast cancer

because the medical literature included no information about the relationship between women's risk of breast cancer and these extended family members' diagnoses with the disease. The two were included because several women in the interviews referred to experiences with friends or extended family going through breast cancer experiences. The researcher anticipated that some women might write in these individuals because the women wanted to acknowledge the impact of these loved one's ordeals on their views of breast cancer.

Internet use questions. Interviewed women who used the Internet said they used it for many purposes, including communication, entertainment (games and music), and information-seeking. The women suggested that the Internet replaced many of the tasks and chores they once had to do differently, such as going to the library for research, talking to a doctor about a health condition, or opening a paper map for directions.

Question 9 on the survey was based on this theme of multiple uses for the Internet. It asked women, "What do you do on the Internet?" A list of items was available for women to select from, if they used the Internet for those purposes. Items on the list included those that interviewed women cited – information, maps, playing games, listening to music, helping children with homework, looking for jobs, sending and receiving email, and reading news – that are also included on Pew Internet polls about people's online activities (Pew Internet, 2009).

Question 6 also related to Internet use and served as a stratification variable. This item asked women to indicate how much time they spent online in a typical week. The options included no time, under three hours, between three and seven hours, and more than seven hours per week. Although other ways to approach this measurement would be to ask women to write in a discrete time or estimate how much time they spent on the Internet in the last week, the

researcher decided that the limitation of atypical online activity in the preceding week would outweigh the precision of the other two approaches.

Another question that is common on online activity polls is where people use the Internet. In the interviews, the theme of convenience emerged as a reason why women used the Internet. Many of the women said they had the Internet in their home and liked being able to use it whenever they wanted to. Question 7, “Where do you use the Internet?” asked women to select from a list including home, work, library, and somewhere else (such as a friend’s house or community center). Women could also check that they did not use the Internet.

Internet non-use questions. The interviews revealed that for women who did not use the Internet, or did not use it much, time and lack of physical access were the primary reasons for non-use. Therefore, Question 8 asked women, “If you don’t use the Internet, why don’t you?” Listed as possible options were both logistical and financial aspects of Internet use and beliefs about the Internet and Internet skills and self-efficacy. A lack of time and not owning a computer or affording Internet service were options related to physical access. A skill and self-efficacy explanation was not knowing how to use the Internet and, to an extent, having somebody else look on the Internet for the respondent. The latter is also commonly asked in online information-seeking polls such as those from the Pew Internet and American Life Project (Fox, 2006).

Beliefs about the Internet. Beliefs about the Internet itself were represented by three statements: I don’t trust the information, the Internet is slow, and there’s too much information.

Efficacy for seeking breast cancer prevention information on the Internet. The question resulted from post-interview analyses during which the researcher realized that interviewed women’s answers to questions about their Internet beliefs did not include references to self-efficacy. It was decided that women’s beliefs about the Internet as a source of good

information did not necessarily equate to women's beliefs that they could find good information on the Internet.

This item was used to measure what women believed about their abilities to find information about breast cancer prevention on the Internet easily. This measure explored impressions of the Internet beyond what women think it is (such as a reservoir of cancer information, which even women who do not use the medium might believe), but also the women's views of their own abilities to use the Internet to find the information they need or want.

Preference for tailored or general breast cancer Web sites. Consistent with the notion of surveys complementing interviews is the opportunity to use surveys to explore concepts that were not clear in the interviews. Preference for tailored or general breast cancer Web sites was not an interview theme because there was no agreement with either preference. Some women said they would rather have a Web site for all women, whereas others thought they might prefer one specifically for African-American women. This question sought to examine what the surveyed women preferred.

Theme Questions

Theme questions are those that arose directly from major themes or subthemes in the interviews. The survey questions do not match the wording of the interview questions, due to the different formats, but they were designed to explore themes and relationships that emerged from conversations with the women.

Health information-seeking on the Internet is a common activity. The study was primarily about women seeking online information about preventing breast cancer, so the survey required questions specifically about that topic. However, the infrequency of those searches by interviewed women prompted a broader look at health information. The questions' conceptual

progression was this: 1) Are women looking for breast cancer prevention information on the Internet? If they are not looking for this information on the Internet, are they looking for 2) prevention information about other diseases and/or 3) information about breast cancer in general? Perhaps, as the interviewed women suggested, women do not look for information about preventing conditions they do not presently have.

Based on this line of thought, the survey included one general question asking if the women “have ever looked for information about a health problem or a disease.” This question was not specific to the Internet because some women do not use the Internet but may be health information seekers. Question 2 asked women if they had ever looked for information about ways to keep themselves from getting a health problem or a disease. And the next question asked women which sources they use to find out about health topics. This question is differently formatted from the others’ yes and no answer options, and includes a list of possible media, interpersonal, and health care sources from which women might have sought information.

Moving into online information-seeking explorations, Question 4 asked women if they have ever looked up health information on the Internet and Question 5 asked if they had ever asked someone to look up this information on the Internet for them. From there, questions became more specific to breast cancer information-seeking on the Internet, including whether or not the women had ever looked for breast cancer information on the medium and if they had “ever looked up information about preventing (never getting) breast cancer?”

Prompts for breast cancer information-seeking related to family members’ experiences or personal scares. This theme of women looking for health information in general, and breast cancer information specifically emerged from the interviews. The survey question relating to that theme asked women, “If you looked for breast cancer information on the Internet, what made

you want to find it?” The respondents had answers that included the two theme scenarios – family members developing breast cancer or the women personally having a scare, such as finding a breast lump or a suspicious mammogram – as well as prompts of curiosity, research for a school project, media coverage of breast cancer, and a breast cancer awareness event prompting interest.

A belief that the Internet would be a good source of information about breast cancer, if a woman wanted that information. None of the women interviewed indicated that the Internet would be a bad source of information about breast cancer, although some suggested that opportunities for misinformation persisted across the medium, due to the ease of Web site development by non-authorities on breast cancer. Therefore, two questions originally sought to explore whether women believed they would look for breast cancer prevention information on the Internet, if they wanted that information, and an Internet skills self-efficacy measure. These latter questions had Likert-scale response formats, with Strongly Agree, Agree, Disagree, Strongly Disagree, and No Opinion, as answers. However, it was later determined that the two questions were measuring two different concepts: perceived utility of the Internet for prevention information-seeking and self-efficacy to use the Internet for that purpose. Therefore, the second item is described separately.

Simplicity of searches and the wealth of information. Interviewed women liked the Internet for health information because it has lots of information, it breaks topics down into subtopics, and information is easy to find. Also, they liked generic search engines because of this convenience factor. Interviewed women’s preference for generic search engines was consistent with previously cited research (Fox, 2006). This preference also has important implications for developing tailored and targeted Web sites for African-American women – if they use Google,

Yahoo and similar search engines that generate search results based on popularity formulas, and the keywords they use are simply breast cancer or similar terms, the women may not encountered such Web sites in the first few pages of search results. For this reason, the women were asked to check the Web sites or search engines they had used for health information-seeking, based on those supplied by interviewed women – Google, Yahoo, WebMD, Medline, Mayo Clinic, a doctor's Web site, or another site not listed.

The interviews and, to some extent, the literature discussed in Chapter 3 about Internet features provided some reasons why women who wanted to find out about preventing breast cancer might turn to the Internet. Most of these reasons related to the reasons the interviewed women said they used the Internet for other health information-seeking. The list included that the Internet has a lot of information; the Internet is fast; the Internet makes it easy to find answers to questions; the Internet lets me read about other women who had breast cancer; the Internet gives me information I can share with my doctor or ask him/her about; the Internet lets me talk about breast cancer with other women through email and chats; the Internet has information that is easier to understand what my doctor tells me; and that the Internet can be used from home, at any time of the day.

Conversely, women were asked if they would not use the Internet for breast cancer prevention information, what their reasons would be. The answer options were, like those related to overall Internet use, logistic, economic, self-efficacy, and belief-based. The list included the following: I don't have a computer with Internet access; I don't know how to use the Internet; I don't trust the information on the Internet; I can't find the answers to my questions on the Internet; the Internet has too much information; the language on web pages is confusing; another reason not listed.

Fear of cancer. Interviewed women frequently cited fear of cancer in general, and breast cancer specifically. Sometimes the fear was mentioned in the context of what the women thought other women might experience with cancer. This theme was consistent with Champion and colleagues' (2008) scales about mammography beliefs that they adapted for African-American women. From Champion and colleagues' (2008) mammography scales came this study's questionnaire item 25: The treatment I would get for breast cancer would be worse than the cancer itself. This was a Likert-scale formatted statement to which women indicated their level of agreement. It was included in the survey because interviewed women suggested that, for some cancers, concern about treatment side effects such as breast removal and sexual dysfunction, were some reasons women did not talk about cancer prevention or did not seek prevention.

Another Likert-style item created and added to the survey was item 26: "Being afraid of breast cancer would keep me from looking for information about preventing breast cancer." This item was another attempt to gauge women's beliefs about actively seeking prevention. It was largely based in the literature that suggests that some people – blunters – intentionally avoid seeking information about health risks, while others – monitors – actively seek or scan available sources for risks (Case, et al., 2005). The interviews also revealed that women thought people viewed breast cancer as something to be feared. This survey question was used to assess whether or not fear of breast cancer might be a barrier to women trying to learn more about the disease.

These two questions both involved fear beliefs that might affect a woman's behavior regarding breast cancer prevention and prevention information-seeking. However, as Chapter 7's limitation section discusses, the underlying concepts of fear of treatment and fears as barriers to information-seeking may be fundamentally different.

Proximity to breast cancer. The women held the belief that risk is mostly associated with family history. The interviewed women implied that they thought they were at low risk for breast cancer if they did not have a family history of the disease. In addition, many women suggested that they did not know what else besides smoking and possibly obesity might increase a woman's risk of breast cancer. Question 11 asked women to check from a list of items or to write in an alternative item they believed puts people at risk for breast cancer. Most of the items came from the interviews, including the myth about breast trauma one woman believed, but others were added from the literature (e.g. ACS, 2009b) to present more options and to determine whether the women's beliefs were consistent with the interviews and with some of the science related to breast cancer. The list was not exhaustive and did not include some items that would have been more difficult to explain in a short answer, such as those related to women's birthing patterns. However, other items listed as things that might increase women's risks of breast cancer included having a family member who has or had breast cancer; the foods they eat (diet); being overweight; smoking; having a breast hit or pulled; growing older; alcohol overuse; something in the environment, and nothing – it just happens to some people.

As mentioned, interviewed women focused on family history as being the primary risk factor for breast cancer. Many of them viewed breast cancer risk as uncontrollable or unable to be changed with prevention. Women without family histories viewed themselves as unlikely to get breast cancer. Women also interpreted prevention as a secondary function in that women can detect tumors early, as opposed to preventing their development. Because of this, several survey items attempted to measure women's perceptions of personal risk. Items 20, 21, and 23 asked the following: "I can do something to keep from getting breast cancer," "I believe I will get breast cancer during my life," and "Compared to other women my age, my chances of getting breast

cancer are higher.” These were Likert-scale items that were compared with respondents’ reported family experience with breast cancer. The intention was to see if women reporting family histories of breast cancer had higher perceived risks of the disease than women without this history. The three items were compared with the family history variable.

Frequency of secondary prevention behaviors. Almost all of the women interviewed had had at least one mammogram. The women’s reasons for this screening varied, with some taking advantage of free tests even though they expressed low perception of risk and other women having a higher perceived risk and getting the mammograms as a precaution. Two questions were included with yes and no answer options to determine how many women in the survey had had mammograms or engaged in monthly self-examinations. This measure was, in part, a demographic-type assessment to see how common secondary prevention behavior was. Even though this behavior is not part of primary prevention, active prevention of breast cancer in any form may indicate general orientations toward prevention. Those two items, questions 39 and 40, asked, “Have you ever had a mammogram or another test for breast cancer?” and “Do you do monthly self-exams for breast cancer?”

A belief in secondary prevention. Some of the interviewees indicated a belief that breast cancer is no longer a death sentence; that it is treatable. Champion and colleagues’ (2008) Likert-scale items about mammogram beliefs included two about the efficacy of mammograms. These items were included in part to see if surveyed women believed in a benefit from any “prevention” at all, or if they believed breast cancer is a death-sentence, as some interviewed women thought older generations believed. The two items were (item 22), which asked, “I believe if breast cancer is found early, it can be treated successfully,” and (item 24), “Having a mammogram will decrease my chances of dying from breast cancer.”

Importance of breast cancer relative to other diseases and problems in the community. This theme occurred in the literature (e.g. Moy, et al, 2006) and in the interviews. Women perceived breast cancer to be less common in their communities, and therefore less of a priority. In order to see if the women in the survey had similar perceptions, they were asked to check the three problems that were the biggest concerns for their community. The women were not asked to rank these items, only to check three of them from the list. Options included an “other” and opportunity to write in a problem that was not listed, in addition to some of the diseases and conditions that came from the literature and interviews. HIV/AIDS; high blood pressure; diabetes; abuse; sickle cell anemia; other cancers; and breast cancer were some of the answer options.

Infrequency of interpersonal discussions about breast cancer. Question 10 asked surveyed women if they had ever talked to friends and family members about breast cancer. This yes or no question was included because women in the interviews reported that they would be unlikely to talk about breast cancer unless they or someone close to them developed it. The question’s purpose was to compare its responses to women’s self-reported breast cancer family history to see if more women with this history talked about the disease than women without the history.

No reported preference for tailored breast cancer Web sites. Many of the interviewed women expressed that they did not care if a breast cancer Web site specifically addressed African-American women. The researcher included Question 18, which asked, “If you wanted information about preventing breast cancer, would you want a web site that talked about breast cancer in African-American women or in women in general?” in an effort to see if this theme carried over to survey respondents. She did not know if the interview responses were influenced

by the women being interviewed by a Caucasian woman, so she posed this question under survey conditions where women could answer anonymously. The three answer options for this question were women in general, African-American women, and it wouldn't matter to me.

Survey Sampling

The survey method used in this study was purposive, non-probability sampling (Babbie, 1990), allowing the researcher to better select survey settings that included women meeting the study parameters. The main reason why this study used purposive sampling was that the study participant parameters were somewhat narrow, using age, race, and gender as conditions of the study. African-American females accounted for only about 6.5% of the U.S. population in 2000, with an even smaller percentage being between the ages of 35 and 65 years (McKinnon & Bennett, 2005) and another slight reduction in the study's conceivable study population based on some portion of these women having survived breast cancer, thus not being appropriate for the study. Random sampling techniques such as random digit dialing would have resulted in a high expenditure of time and effort in order to yield significant numbers of participants meeting the study's criteria. Despite this low percent of their population representation, African Americans are disproportionately low income, representing nearly one quarter of Americans living below the poverty line in 2000 (McKinnon & Bennett, 2005). This income variable may affect the likelihood of women meeting the study's focus parameters having telephones or long term addresses, so random selection for phone or mail surveys also would have been problematic.

Even before developing the survey instrument, the researcher expected to be interested in receiving data from women with and without breast cancer in their families and from women who do and do not use the Internet. Focusing sampling efforts in a purposive way so that most or all survey respondents fit the initial gender, race, age, and no breast cancer diagnosis parameters allowed the researcher to get more usable and useful data for inferences. Kemper echoes this idea

by explaining that purposive, non-probability sampling allows researchers to select “specific cases that will provide the most information for the questions under study,” (2003, p. 279).

The sampling technique was opportunistic and snowball sampling. Absence of probability in sampling design prevents researchers from making inferences about the survey findings’ distribution in the larger population, but it allows researchers to get more cases to explore the themes. Although these types of purposive, non-random sampling reduce researchers’ ability to make generalizable inferences and to make the kind of strong statements about the data’s relationships as are often seen in purely quantitative pursuits, this method is not inconsistent with the qualitative paradigm of selecting cases based on qualities that will inform the understanding of a phenomenon. Even though the survey itself is quantitative, due to its close-ended questions and opportunities to count cases, its purpose and design remain exploratory. Additionally, it was necessary for this younger, white researcher to seek help from informants in the community who are African-American women within the study’s age ranges and who could assist with identifying cases for the study.

Kemper says this type of sampling “use[s] insider knowledge to maximize the chance that the units included in the final sample are strong (highly appropriate) cases to include in the study” (2003, p. 283). Snowballing begins with one or two participants matching the study’s description and asks them to identify more participants to be part of the research. Less defined is opportunistic sampling, which Kemper describes as “taking opportunities as they come along and following up on leads as they arise within fieldwork” (2003, p. 283).

Sample size in quantitative studies should be estimated based on the need for data from subgroups being studied (Fowler, 2002). In describing quantitative studies, Fowler says, “Most sample size decisions do not focus on estimates for the total population; rather, they are

concentrated on the minimum sample sizes that can be tolerated for the smallest subgroups of importance” (2002, p. 36). Estimating sample size for this study was more complicated. The survey phase sought responses from women of various ages within the study’s range who had different Internet use patterns and a mix of family breast cancer history statuses.

As implied in the mixed methods section of this paper, the researcher had to make many decisions about the study’s purpose and design. The fact that the study is sequential as opposed to concurrent; exploratory and not explanatory; qualitative inquiry followed by the quantitative method; qualitative perspective dominant as opposed to equally weighted between qualitative and quantitative; etc., gives it a unique design “DNA.” Each of these study attributes has its own underlying perspective that would be violated with haphazard decisions, such as in the case of sampling approaches. As the qualitative paradigm does not seek generalizability of findings, the statistical formulas often used to determine sample sizes in quantitative research were not appropriate for this exploratory study with a non-purposive sample.

Without a sampling formula, the researcher consulted literature for guidance in determining an appropriate sample size. As previously described, every mixed method study may become a distinctly different design from another mixed method study by choosing a different research stance. The literature includes examples of mixed method studies using interviews and surveys, but because existing studies did not have the same attributes of this particular study, they offered little direction for sampling size. Morse (2003) points out that when emphasis is placed on one phase instead of treating the qualitative and quantitative portions as equal, the less dominant research method portion is not considered a complete and separate study. Findings from the less dominant data collection phase (the quantitative portion of this study) do not need complete verification, and saturation is not required (p. 196). The main anticipated determinant

of sample size for this study was the desire to explore many themes and subgroups. Sampling decisions reflected this interest in seeing rich data from people with multiple backgrounds and experiences (e.g. Internet experience, family history, and perhaps sociodemographic indicators). It was decided before the survey data collection phase that approximately 150 surveys would provide that information.

Surveys were administered to 259 women in one large Southern city with an MSA population of more than one million and in one small Southern city with a population of about 10,000 people, in order to get a variety of responses. Church pastors and individuals affiliated with local health care services and cancer non-profit organizations served as initial contacts for identifying women, and groups of women, who might complete the survey. Some of these contacts suggested group meetings and events where the researcher distributed and collected surveys on site. When no convenient meeting or venue was available, the researcher left copies of the survey for any interested woman to complete at her leisure and return to the researcher's post office box in a confidential, pre-stamped, addressed envelope. Eighty-four surveys were distributed with mailing instructions, of which 19 were returned. The response rate was 22.6% for that method. Surveys were administered in person as well. For the on-site method, it is estimated that only two of the 175 surveys were taken but not returned. Thirty of the surveys collected through both methods were eliminated because the respondents answered that they were outside the study's age parameters or the respondents were breast cancer survivors, leaving 160 surveys in the sample.

The surveys were analyzed at the end of the collection process. Then the survey findings were presented separately from the qualitative results in Chapter 6.

Survey Analysis

To remain consistent with the qualitative paradigm and the interpretation of nonprobabilistic sampling, statistical inferences about the strength of relationships between variables were limited. However, descriptive statistics and other analyses were used to examine the relationships between variables in order to further explore the themes (Johnson & Turner, 1993). Variables explored included answers to questions about Internet use and non-use, health information-seeking, breast cancer information-seeking, beliefs about breast cancer risk factors, respondents' perceptions about personal risk of breast cancer, efficacy of prevention, family history of breast cancer, and other demographic data, such as education and income levels.

Analyses varied by variable level. All of the demographic questions, including the one about women's breast cancer family history, were first analyzed with descriptive statistics to show frequencies. Ordinal variables, including education and income level, and nominal variables such as relationship status and breast cancer family history, were described by number and percentages of cases they represented within the sample. Age, the only continuous variable, was also assessed with measures of central tendency.

Further analyses depended on the appropriateness of measures to each variable and research question. The three analyses and accompanying tests of significance and association used in the paper were Chi-square with cross-tabulated nominal and nominal or ordinal variables, independent-samples *t* tests to compare means of two groups of nominal variables, and Spearman's rank correlation coefficient to examine ordinal variables. The purpose of the Chi-square test is to examine whether apparent relationships between variables are significant or are likely due to chance, based on the distribution of actual survey responses compared to expected distribution if no relationship existed (Babbie, Halley, & Zaino, 2003). The *t* tests (two tailed in all cases within this survey) allow researchers to examine means of responses between two

different groups, such as male and female or someone with a breast cancer family history and someone without a breast cancer family history, and see if any observed differences in means are likely significant or the result of the sampling used. The p value indicates whether a statistically significant association between measured variables exists. Spearman's statistic for correlations allows researchers to assess if two ordinal variables are associated, the direction of the relationship, the strength of the relationship, and the significance level. The rest of this analysis section will describe which tests were used to answer each research question, based on the survey data.

The first research question about women's beliefs about breast cancer was assessed by running frequencies for the risk factors women cited in survey question 11, in order to see what women believed put a person at risk for breast cancer. Frequencies of cited risk factors were also examined and presented separately for women with and without family histories of breast cancer to see if differences existed in what these women thought put women at risk of breast cancer. Cross-tabulation with the Chi-square statistic was performed to see if any statistically significant relationships existed between family history of breast cancer and the factors women believed put one at risk for the disease.

Another analysis used to examine factors influencing beliefs was a correlation using Spearman's rank correlation coefficient statistic (r_s) to explore how income, education, and age related to the five Likert-scale questions about a woman's beliefs about her perceived risk of developing breast cancer and beliefs about prevention. The prevention belief questions were: "I can do something to keep from getting breast cancer," "I believe if breast cancer is found early, it can be treated successfully," and "Having a mammogram will decrease my chances of dying from breast cancer." Beliefs about perceived personal risk of cancer included the following: "I

believe I will get breast cancer during my life,” and “Compared to other women my age, my chances of getting breast cancer are higher.” Descriptive statistics for the answers were presented. The Spearman’s rank correlation coefficient was useful to see if agreement with the beliefs was correlated with higher levels of age, education and income.

The second research question asked about how communities treated or viewed breast cancer. The surveys could not fully answer that question, as it was clearly written from a qualitative perspective; however, the surveys offered an opportunity to see which diseases and health problems women thought were most common in their communities. Frequencies were run for the problems women checked as the top three priorities. Then, to see if women with breast cancer family histories might perceive breast cancer to be a bigger priority than women without this history, a cross-tabulation with the chi-square statistic was used with the family history variable. Further exploration of these relationships was not appropriate due to the small subsample (n=37) of women with family histories of breast cancer.

Also for Research Question 2, the results of the survey question about whether women talked to friends or family members about breast cancer was described with frequencies and then cross-tabulated with family history of breast cancer to see if, as was the case in the interviews, the women who had this history were more likely to talk about the disease due to this experience with loved ones. Both of these variables were nominal so the Pearson’s Chi- square statistic was used to test for statistical significance between talking about breast cancer and having a family history of the disease.

To answer Research Question 3 about breast cancer prevention information-seeking, frequencies were run for the information-seeking questions (about health information-seeking, prevention information-seeking, breast cancer information-seeking, and breast cancer prevention

information-seeking) and then cross-tabulated with the family history variable to see if differences existed according to this history, using the chi-square statistic. Frequencies were also examined on the health information sources mentioned to see where the women were finding out about health topics and if these sources differed by breast cancer family history. Chi-square values revealed where there were significant differences in sources by family history.

Research Question 4 sought to discover more about how the women used the Internet. First, women's responses to time spent online were examined with frequencies. Of particular interest to the researcher were the reasons women who do not use the Internet give for their non-use. The cases of women who said they spent no time on the Internet in a given week were probed with the question about why they do not use the medium by running frequencies for the answers. Frequencies also were used to show where the women used the Internet.

In an effort to see if there was a correlation between survey respondents' ages and the time they spent online, Spearman's rank correlation coefficient was used to examine relationships between these two variables. Similarly, correlations were examined to determine if there was a relationship between education or income and time spent online. Frequencies were run for the online activities surveyed women said they did. A chi-square test indicated whether or not the age, income, and education level variables were significantly related to the most relevant activity – looking up information.

Research Question 5 concerned breast cancer information-seeking. An earlier research question (RQ3), showed frequencies for breast cancer online information-seeking. For RQ5, the prompts for these breast cancer information searches were explored by selecting only the cases of women who had looked for the information and running frequencies for the prompts. The reason for this filter is that some women marked that they had not looked for breast cancer

information on the Internet but did mark some reasons why they looked for breast cancer information. This selection filter allowed the researcher to examine only the cases where the answers were consistent for both questions. Three of the Likert-style scale questions that related to Internet use for breast cancer information were examined using Spearman's rank correlation coefficient to note any significant correlations between these beliefs and age, education, and income.

For Research Question 6, frequencies explored the most common Web sites and search engines women used to find health information. Then frequencies analyzed reasons why women reported they would use the Internet for breast cancer prevention information, if they wanted that information. Chi square statistics looked for significance between those reasons and women's age, education, income, and family history. Frequencies were also used to explore reasons women reported for why they would not use the Internet to find breast cancer prevention information, even if they wanted that information.

The reasons to or not to use the Internet were computed into new variables so that if a woman cited any reason she would use the Internet for breast cancer information, the new variable reflected a case of women who have a reason to use the Internet, where 1 represented this state and 0 represented cases where women did not mention a reason. The same computation was used for the question asking women for reasons they would not use the Internet for this information. Then the new variables were cross-tabulated with time spent online and family history of breast cancer.

Frequencies were also run for the topics of breast cancer information women would want to find on the Internet. Only frequencies were run here because the answers were not exclusive – women could select many of the topics from the list instead of choosing only one or ranking their

selections in order of importance. However, the topics selected were also cross-tabulated with breast cancer family history to see if that variable was statistically related to desires for different information about the disease.

Research Question 7 was explored by comparing responses to the individual scale questions by the family history variable to look for differences in beliefs held by women with and without breast cancer family histories. Family history was treated as a dichotomous variable, with women who had a family history of breast cancer and those who did not. T-tests were used to compare the mean responses of women without this history to women with the history.

CHAPTER 6
SURVEY RESULTS

Survey Results

One hundred and sixty surveys were included in the final dataset. All of the surveys represented self-reported female African Americans. The breakdown of respondents' reported annual household incomes, highest education level completed, age, and relationship status appear in Table 6-1. The average age was 54.8 and the median age was 49.

Table 6-1. Survey respondents' age, education level, income, and relationship status

Variable	n	%
Yearly household income		
Less than \$20,000	42	29.2
Between \$20-50,000	66	45.8
Between \$50-75,000	24	16.7
More than \$75,000	12	8.3
Highest education level completed		
Middle school	7	4.7
High school	90	60.8
College	32	21.6
Graduate school	19	12.8
Age		
35-39	24	16.0
40-44	31	20.7
45-49	36	24.0
50-54	28	18.7
55-59	24	16.0
60-65	7	4.7
Relationship status		
Single, never married	32	20.0
Married	89	55.6
Living with a partner	3	1.9
Divorced	24	15.0
Widowed	12	7.5

The highest percentage of women surveyed (45.8%, n = 66) reported a yearly income of between \$20,000 and \$50,000. A majority (60.8%, n = 90) of surveyed women had high school degrees but no further education. More than half (55.6%, n = 89) said they were currently married.

RQ 1: How do the women describe their beliefs about breast cancer and breast cancer prevention? The survey results reflected the belief that family history puts one at risk for breast cancer. Approximately 71% (n = 113) of the surveyed women indicated they thought family history is a risk factor. Family history was the most commonly marked risk factor, followed by smoking (50.6%, n = 81), diet (39.4%, n = 63), and a tie between “being overweight” and “nothing, it just happens to some people” (28.8%, n = 46). Growing older, a major factor in breast cancer risk, was marked by only 28 women (17.5%). Table 6-2 shows the risk factors in order of their frequency.

Table 6-2. Frequency of perceived risk factors for breast cancer in total sample and by family history

Risk Factor	Total Sample		Family History		No Family History	
	n	%	n	%	n	%
Family history	113	70.6	33	89.2	80	65.0
Smoking	81	50.6	16	43.2	65	52.8
Diet	63	39.4	17	45.9	46	37.4
Overweight	46	28.8	12	32.4	34	27.6
Nothing	46	28.8	14	37.8	32	26.0
Environment	32	20.0	6	16.2	26	21.1
Growing older	28	17.5	7	18.9	21	17.1
Breast hit/pulled	17	10.6	5	13.5	12	9.8
Alcohol	15	9.4	0	0.0	15	12.2

The three most common risk factors indicated are the same for women with and without family histories. However, the order and percentages of two risk factors were different, with women who have breast cancer family histories ranking smoking above overweight, and women without a family history marking overweight above smoking as a risk factor. Also important is

the higher percentage (89.2%) of women with relatives who have had breast cancer indicating that they thought family history was a risk factor, compared to women without this personal family history (65%).

Despite these different percentages for women with and without family histories of breast cancer, only two of the differences were statistically significant. Family history of breast cancer status had a statistically significant relationship with the beliefs that family history is a risk factor for the disease ($\chi^2 = 7.995, p < .005$) and that alcohol use is a risk factor ($\chi^2 = 4.979, p < .03$).

Five Likert-scale questions assessed women’s beliefs about their perceived risks of developing breast cancer and beliefs about prevention. Table 6-3 shows the means, standard deviations and other measures for these five questions.

Table 6-3. Descriptive statistics for beliefs about perception of personal risk and beliefs about breast cancer prevention

Survey item	n	Mean	SE	SD	Variance
Compared to other women my age, my chances of getting breast cancer are higher.	116	2.43	.08	.86	.73
I can do something to keep from getting breast cancer.	127	2.09	.08	.89	.80
If breast cancer is found early, it can be treated successfully.	154	1.49	.05	.62	.38
I believe I will get breast cancer in my life.	96	3.17	.08	.79	.63
Having a mammogram will decrease my chances of dying from breast cancer.	140	2.06	.07	.82	.67
The treatment I would get for breast cancer would be worse than the cancer itself.	111	2.96	.07	.78	.61

The researcher wanted to see if any correlations existed between these beliefs and the variables of age, income, and education level (see Table 6-4). Only one item revealed statistically significant results. There was a small correlation between income and belief that one is at higher risk of breast cancer ($r_s = .205; p < .05$). Even though this statistic suggests a positive relationship, the sign is an artifact of the measurement; in all of the beliefs scales, strongly agree was coded as 1 and strongly disagree was coded as 5. Therefore, higher income is correlated with lower beliefs that one is at risk for breast cancer.

Table 6-4. Correlations between age, education, and income, and beliefs about personal risk of breast cancer and beliefs about prevention (r_s)

Survey item	Age	Education	Income
Higher chances	-.11	.07	.21*
Do something	-.02	.12	.06
Early detection	-.08	-.05	-.05
I will get breast cancer	-.04	.12	.17
Mammogram	-.07	-.10	-.11

* $p < .05$

RQ 2: What individual, interpersonal and cultural factors influence African-American women’s beliefs about breast cancer prevention? What do they think breast cancer means to their communities? How do members of their social sphere and community talk about breast cancer? Surveys revealed that other diseases were more predominant or bigger priorities in participants’ communities. Women were asked to check the three problems that were the biggest concerns for their community from a short list of common health issues that came from the literature and interviews, as well as the option to check “other” if the list was not inclusive enough. The three most common health problems checked on the surveys were high blood pressure ($n = 136, 85\%$); diabetes ($n = 118, 73\%$), and HIV/AIDS ($n = 79, 49\%$). Table 6-5 has a complete list of cited problems. By comparison, breast cancer was only listed as a top-three disease priority by 29 women (18%). Even among women who had a family history, breast cancer was only marked by 22% ($n = 8$). Women with a family history of breast cancer were not significantly more likely to select breast cancer as a priority problem in their communities ($\chi^2 = .397, p > .528$).

Table 6-5. Problems facing respondents' communities, by number and percent of women who cited the problems as top three priorities

Problem	n	%
High blood pressure	136	28.1
Diabetes	118	24.4
HIV/AIDS	79	16.3
Heart disease	55	11.4
Other cancers	34	7.00
Breast cancer	29	6.00
Other problems	15	3.10
Abuse	10	2.10
Sickle cell anemia	8	1.70

Among the survey responses, 78% (n = 126) of surveyed women indicated that they had talked to friends or family members about breast cancer. Among women with a family history of breast cancer, 95% (n = 35) said they had talked about the disease; 74% (n = 90) without this history said that they had talked about breast cancer. Chi-square tests revealed that this difference may be significant ($\chi^2 = 7.221, p < .01$). This questionnaire item was a simple yes or no question, allowing the researcher to infer no more details or insights about the way women talk about breast cancer, what prompts the conversation, how regularly it is discussed, what is said in conversations about the disease, and how the survey results compare to the interviews.

RQ 3: What emphasis do women place on personal, proactive breast cancer prevention information-seeking? The survey did not ask women about breast cancer information-seeking from any source; rather it focused on the Internet for that information. Less than one third (30.3%, n = 37) of survey participants who did not have a family history of breast cancer indicated that they had actively sought breast cancer information on the Internet, whereas slightly more (38.9%, n = 14) of the women who had a mother, sister, or grandmother with the disease had searched (Table 6-6). Chi-square tests revealed that the relationship between family history of breast cancer and breast cancer information-seeking on the Internet was not statistically significant.

Table 6-6. Use of the Internet for breast cancer information

Breast cancer information-seeking status	Women with no family history	Women with a family history	Total
Has never sought breast cancer information on the Internet	85 (69.7%)	22 (61.1%)	107 (67.7%)
Has sought breast cancer information on the Internet	37 (30.3%)	14 (38.9%)	51 (32.3%)
Total	122 (100%)	36 (100%)	158 (100%)

Three most commonly mentioned sources from which women find out about health topics are their doctors (75%, n = 120), television (61%, n = 97), and from friends and family members (60%, n = 96; see Table 6-7). While women may actively seek out health information from these sources, the most common sources accommodate passive information attainment, as opposed to actively seeking information in books or on the Internet. Women may actively seek health information from their friends and doctors but they also may receive unsolicited advice about health when they go to medical offices for annual check-ups or when they engage in conversation with family members and friends.

Table 6-7. Women's sources of health information

Source	N	%
Doctor	120	75.0
Television	97	60.6
Friends & family	96	60.0
Books	88	55.0
Internet	80	50.0
Work	53	33.1
Health fairs	48	30.0
Hospital	43	26.9
Radio	40	25.0
Church	31	19.4

Sources of information about health topics did not vary much according to women's family history of breast cancer (see Table 6-8). None of the relationships between specific sources of information and family history were statistically significant.

Table 6-8. Number and percent of women who said they found out about health topics from each source of information, by family history of breast cancer

Sources of health information	Women with no family history	Women with a family history
Doctor or hospital	91 (75.2%)	27 (73.0%)
Television	74 (60.2%)	23 (62.2%)
Radio	28 (22.8%)	12 (32.4%)
Friends	71 (58.7%)	24 (64.9%)
Health fairs	35 (28.9%)	12 (32.4%)
Church	22 (18.2%)	7 (18.9%)
Internet	59 (48.8%)	21 (56.8%)
Work	39 (32.2%)	12 (32.4%)
Books	68 (56.2%)	19 (51.4%)

Despite this low breast cancer information-seeking, 87.5% of surveyed women said they had searched for health information in general (n = 140), and 83.1% (n = 133) had looked for prevention information from some source about some disease or condition. However, only 34.4% (n = 55) of the women said they had ever sought out information about preventing breast cancer. Only 50% of the survey respondents (n = 80) said they find out about health topics on the Internet, but 65% (n = 104) said they had looked up health information on the Internet, a discrepancy that may be explained by semantics: the question asking women if they find out about health topics implies passive information acquisition whereas the wording in the question asking women if they looked up health information on the Internet was decidedly more active. Regardless, at 32% (n = 51), a lower percentage of women had looked up information about breast cancer on the Internet. While a higher percent of women with breast cancer in their families (39%, n = 14) looked for breast cancer information online than women without this history (31%, n = 37), an earlier finding showed that the difference in rates was not statistically significant.

RQ 4: What do they think about the Internet? How do they describe the Internet's role or importance in their social setting or community? The survey respondents were asked

how much time they spent on the Internet each week, and the most common answer was less than three hours (37.5%, $n = 60$), followed by “no time” at 34% ($n = 55$). Forty-five women (28%) said they spent more than three hours each week on the Internet (Table 6-9). The percentage of women who answered that, during an average week, they spend no time on the Internet (34%, $n = 55$) is higher than the percentage of women who answered another question saying they do not use the Internet at all (23%, $n = 36$); however, the discrepancy could be explained by the two questions’ wording. Given the utility to this study that comes from comparing other variables according to the multiple categories of time spent online, the reported weekly Internet use statistic will be used throughout the results section.

Table 6-9. Amount of time women reported to spend on the Internet in an average week

Time	N	%
No time	55	34.4
Less than 3 hours	60	37.5
Between 3 and 7 hours	32	20.0
More than 7 hours	13	8.1
Total	160	100.0

Age, education and income were all significantly correlated with time spent online, with moderate correlations between each. Age was negatively correlated ($r_s = -.31, p < .01$), suggesting that as age increased in the sample, time online decreased. Education ($r_s = .44, p < .01$) and income ($r_s = .38, p < .01$) were both positively correlated with time spent online, indicating that higher degrees of education and income were related to more Internet use.

Among the 55 women who said they spend no time on the Internet in a typical week, 20 women did not mark a reason for this non-use from the survey list. None said that their reasons for not using the Internet stemmed from a lack of trust of the medium. The two most common reasons given for non-use were not having physical access to the Internet (42%, $n = 23$) and not knowing how to use the Internet (20%, $n = 11$). The only other explanation marked by more than

two people was “I have somebody else [use the Internet] for me,” with about 15% (n = 8) of the women indicating that situation. It is important to note that these categories were not mutually exclusive on the survey instrument, meaning that women may have selected more than one reason to describe why they do not use the Internet (Table 6-10).

Table 6-10. Reasons given for not using the Internet by women who reported spending no time using it in a typical week

Reason	n	%
I don't have access.	23	41.8
I don't know how to use it.	11	20.0
Someone else does it for me.	8	14.5
I don't have time.	1	1.8
I don't trust the Internet.	0	0.0
The Internet is too slow.	0	0.0
The Internet has too much information.	0	0.0

Most of the women who said they did spend time on the Internet in a typical week indicated that they used it at home (88%, n = 92), and 48% (n = 50) said they used the Internet at work. Less popular places to use the Internet were at the library (16%, n = 17) and some other place, such as a friend's house or a community center (9%, n = 9). These categories were not presented as mutually exclusive either; some women used the Internet in more than one of the places. The most common activities on the Web were looking for information and using email (see Table 6-11). Looking up information, the activity relevant to this study, was related to age ($\chi^2 = 10.77$), education ($\chi^2 = 26.44, p < .001$), and income level ($\chi^2 = 14.72, p < .01$), although the relationships were only statistically significant for the latter two.

Table 6-11. Number and percent of women who use the Internet for each activity

Online Activity	n	%
Look up information	89	84.8
Email	80	76.2
Read news	68	64.8
Find maps and directions	60	57.1
Help children with work	46	43.8
Buy things	46	43.8
Play games	32	30.5
Listen to music	26	24.8
Look for jobs	24	22.9

Time spent online and survey respondent's age, as a recoded categorical variable with approximately five years representing each category, were negatively correlated ($r_s = -0.31$, $n = 151$, $p < 0.001$), meaning that older age was correlated with less time online; and respondent's education level was correlated with time spent online ($r_s = 0.44$, $n = 148$, $p < 0.001$) indicating a medium positive correlation between the variables, so that more educated women tended to spend more time online. Also, income was positively correlated with time spent online ($r_s = 0.38$, $n = 144$, $p < 0.001$), with higher incomes correlated with more time using the Internet. None of these correlations were very strong.

RQ 5: What do African-American women think about the Internet as a source of breast cancer information? For women who use the Internet for breast cancer information, how do they describe their experience? Of the 51 surveyed women who said they had sought online information about breast cancer, the three most common prompts to seek that information were having a family member diagnosed with the disease (75%, $n = 38$), having a personal breast cancer scare (39%, $n = 20$), and seeing something in a pamphlet that made them want to find more information (39%, $n = 20$). The question's instructions encouraged women to check all items that applied to them, accounting for the percentages adding up to more than 100%.

Three of the remaining Likert items explored women's beliefs about their potential use of the Internet for breast cancer information. Table 6-12 shows the descriptive for these questions.

Table 6-12. Descriptive statistics for belief items about using the Internet for breast cancer information

Survey item	n	Mean	Std. Dev
Being afraid of breast cancer would keep me from looking for information about preventing breast cancer.	139	3.11	.81
If I wanted to find out what I could do to prevent. breast cancer, I would use the Internet to find that.	135	2.03	.65
I believe I could find information about breast cancer prevention on the Internet easily.	139	1.86	.65

Tests revealed statistically significant correlations between education level and two of these Internet beliefs (Table 6-13). Both demographic variables were negatively and weakly correlated ($r_s = -.19$ for both, $p < .05$). Again, the coding scheme for beliefs assigned higher numbers to disagreement, so the negative direction suggest that higher income and education levels were correlated with less disagreement or more agreement that women would use the Internet to find prevention information, if they wanted that information, and more agreement that they would find the information they wanted easily. This implies that higher education is correlated with higher Internet self-efficacy.

Table 6-13. Correlations of age, education, and income with Internet beliefs (r_s)

Survey item	Age	Education	Income
“Being afraid”	-.07	.03	.04
“Would use the Internet”	.15	-.19*	.08
“Could find information easily”	.04	-.19*	-.11

* $p < .05$

RQ 6: What features or characteristics of the Internet enhance or deter women’s experiences seeking breast cancer information?

This question was not fully answered in either the interview or the survey, largely because the interviews, as sources of survey question development, indicated that breast cancer information-seeking might be an uncommon activity by women who have never had the disease. Therefore, survey questions helped describe how women search for health information on the Internet and reasons why they might use the Internet for breast cancer prevention information.

Among the 104 women who said they had looked on the Internet for health information, the most popular sites and search engines on the survey instrument were Google (70%, n = 73), Yahoo (67%, n = 70), and WebMD (42%, n = 44).

Women were asked questions about the reasons they would or would not use the Internet to find breast cancer prevention information. Although the researcher's presumption was that women would either choose reasons why they would use the Internet or reasons why they would not use it, some women checked reasons from both categories. Eighty-six percent (n = 137) of all women surveyed indicated one or more reasons why they would use the Internet, and 44% (n = 71) marked at least one reason why they would not use the Internet to find breast cancer prevention information. Instead of attempting to interpret reasons for this overlap in this results section, these results represent the number of times each reason was mentioned.

Women who indicated that they would use the Internet to find information about preventing breast cancer were asked to select all applicable choices from eight reasons or write their own reason why the medium would be an attractive source of information for this topic. At the top of the list of the reasons why they would use the Internet were that the medium has a lot of information (n = 51), the Internet makes it easy to find answers (n = 49), and the Internet lets them read about other women who have had breast cancer (n = 40); however, the next three most common reasons (as Table 6-14 shows) were indicated by 35-38 women, too.

Table 6-14. Percentages of women reporting specific reasons they would use the Internet to find breast cancer prevention information

Reason	n	%
The Internet has a lot of information.	51	37.2
The Internet makes it easy to find answers to questions.	49	35.8
The Internet lets me read women's stories.	40	29.2
The Internet gives me information I can share with my doctor.	38	27.7
The Internet can be used from home, at any time of the day.	38	27.7
The Internet has information that is easier to understand.	35	25.5
The Internet is fast.	27	19.7
The Internet lets me talk about breast cancer with other women.	20	14.6
Other	1	0.7

Chi-square tests revealed very few statistically significant relationships between family history status and reasons why women would use the Internet for prevention information. One significant relationship was between family history and reading about stories of women who experienced breast cancer ($\chi^2 = 8.138, p < .005$). More than 62% (n = 23) of women with family histories of breast cancer reported that they would be interested in this information, compared with only 36% (n = 44) of women without the family history.

Six statistically significant relationships were found between the income, age, and education variables and the characteristics about the Internet that would make the women use that medium for prevention information-seeking. These significant relationships are shown in Table 6-15.

Table 6-15. Significant relationships between reasons for potential Internet use for prevention information and demographic variables (χ^2)

Reason	Age	Education	Income
The Internet has a lot of information.	23.25****		
The Internet gives me information I can share with my doctor.		18.88****	
The Internet can be used from home, at any time of the day.		8.48*	10.63 *
The Internet has information that is easier to understand.		12.77***	
The Internet is fast.		11.28**	

*p<.05, **p<.01, *** p<.005, ****p<.001

The surveyed women were asked to check which of 12 questions about breast cancer they would want to have answered by a Web site about the disease. Anecdotally, the researcher observed that many women checked nearly every listed topic; in fact, the item chosen least by the women – information about hair falling out – was still marked by 40% of respondents (n = 64). Table 6-16 shows the order of items by percent of women who said they wanted questions answered about each topic. Although differences appear in the frequencies, none of the differences were statistically significant for women with and without family histories of breast cancer.

Table 6-16. Number and percent of women who indicated they would want to learn about each breast cancer topic, by women with and without a family history of the disease

Breast cancer question or topic	No family	Family history
	n (%)	n (%)
What causes it?	103 (85.1%)	32 (86.5%)
Warning signs of breast cancer	96 (79.3%)	30 (81.1%)
Does it affect African-American women differently?	85 (70.2%)	25 (67.6%)
Treatment options	79 (65.3%)	28 (75.7%)
Treatment side effects	75 (62.0%)	22 (59.5%)
Diet/nutrition to reduce risks	73 (60.3%)	24 (64.9%)
Personal stories from people with cancer	67 (55.4%)	19 (51.4%)
Survival	63 (52.1%)	18 (48.6%)
Mammography process	61 (50.4%)	18 (48.6%)
How to find support groups	61 (50.4%)	15 (40.5%)
How to get a mammogram if you can't afford one	53 (43.8%)	20 (54.1%)
Hair falling out	52 (43.0%)	11 (29.7%)

The two most common reasons women marked for why they would not use the Internet for breast cancer prevention information were because they did not have physical access to the Internet (n = 29) and they do not know how to use the Internet (n = 18). Table 6-17 lists all of the reasons given in the order of popularity.

Table 6-17. Reasons why women would not use the Internet to find breast cancer prevention information

Reason	n	%
I don't have a computer with Internet access.	29	40.8
I don't know how to use the Internet.	18	25.4
I can't find the answers to my questions on the Internet.	7	9.9
The Internet has too much information.	3	4.2
I don't trust the information on the Internet.	2	2.8
The language on web pages is confusing.	2	2.8
Another reason not listed	0	0.0

When frequencies were run only on the 71 women who mentioned a reason why they would not use the Internet to find breast cancer information, 61% (n = 43) reported spending no time online each week. An additional 30% (n = 21) said they spend fewer than three hours online weekly, suggesting that these women who would not use the Internet for finding breast cancer prevention information do not use the Internet much for any purpose.

RQ 7: Among members of these two groups – African-American women with breast cancer family histories and those without them – are their reasons for using or not using the Internet more related to their beliefs about breast cancer or to their beliefs about the Internet? The question about influence remains difficult to answer because of its inherent formulaic phrasing. For one thing, the question implies that behavior would be influenced by one set of beliefs or the other, when a combination is likely involved. To what extent knowledge, socioeconomic factors, health status, social norms, faith, and other variables interplay to mold a woman's beliefs about the disease's prevention is unknown and undiscoverable with the present survey sample size.

Identifying influencing factors was difficult because most interviewed women answered not in terms of preventing the incidence of breast cancer but in reference to early detection efforts, in hopes of saving the patient's life. In fact, the emphasis on inherited risk factors across the interviews suggested that some of the demographic differences in the women, such as age,

marital status, and education level, likely played very little to no role in how they perceived breast cancer prevention. The researcher hoped the survey portion of the study would provide more clues about differences in breast cancer and prevention beliefs among women in various demographic categories. However, the results failed to shed light on potential measurable influences because the scales were unreliable, likely due to the low number of items in each proposed scale and possibly some face validity issues.

Instead of comparing breast cancer family histories to the scales, responses to each Likert-scale question were compared with family history. Family history was treated as a dichotomous variable and *t*-tests were performed. There was no significant relationship between these beliefs and family history of breast cancer except for the belief statement that one is at higher risk for developing breast cancer than other women. For this belief, the mean for women without a family history of the disease was 2.54 (*SD* = .832, *n* = 87) and 2.10 for women with family histories (*SD* = .859, *n* = 29); $t(114) = 2.43, p < 0.018$, indicating that women who had a family history of breast cancer perceived their own risk as higher. This result should be viewed with some caution because the total response rate for that question was only 73%.

Integration of Interview and Survey Results

The interviews and surveys examined the study's research questions from very different perspectives. The interviews included open-ended explorations of women's beliefs whereas surveys presented participants with limited number of options from which to choose. Interpretation of answers to research questions reflects this difference. For example, the interviews allowed the researcher to ask women the equivalent of "what do you believe about breast cancer?" The surveys basically asked participations "of these listed items, what do you believe about breast cancer?" As such, interview and survey results are not direct comparisons; however, together they provided a more comprehensive look at the research questions.

RQ1: How do the women describe their beliefs about breast cancer and breast cancer prevention? Study participants in the interview and survey portions both emphasized family history as the predominant risk factor for breast cancer. Family history was mentioned by all of the interviewed women and cited as a risk factor by more than 70% of surveyed women.

The nature of the interviews did not allow the researcher to distinguish certain factors that might have influenced the women's beliefs about breast cancer. However, in general, the women interpreted prevention to be secondary level prevention methods. The belief about family history being the biggest risk factor may have led to this interpretation that breast cancer cannot be prevented, only detected early and treated. Two survey questions' answers point to more ambiguity than clarity on this issue about prevention levels. One item, "I can do something to keep from getting breast cancer," implied a primary prevention level. The mean for that answer was 2.09, representing a point between agreement and disagreement with that statement. Although response rates were higher, a mean of 1.49 for the statement "If breast cancer is found early, it can be treated successfully," points to a stronger belief in secondary prevention. Most of these beliefs were not significantly correlated with age, income, and education for the survey participants.

RQ2: What individual, interpersonal and cultural factors influence African-American women's beliefs about breast cancer prevention? What do they think breast cancer means to their communities? How do members of their social sphere and community talk about breast cancer? The interviews revealed that the belief that breast cancer was related to family history was rather common across participants, including those with and without family histories of the disease. Surveys echoed this finding that women perceived family history to be the biggest risk factor for breast cancer. On an individual demographic level,

income was the only variable that was significantly related to beliefs about one's chances of getting breast cancer. Lower income women tended to believe more strongly that they were at risk for the disease.

Both the interviews and surveys revealed that other diseases and problems were more prevalent or bigger priorities in the women's communities. Specifically, high blood pressure and diabetes were often mentioned in the interviews and cited on the surveys. The prevalence of diseases seemed to influence women's perception of those health conditions as community concerns.

The interviewed women without breast cancer history suggested that they would be unlikely to talk about the disease unless it affected them or a loved one. A higher percentage of women with family histories in the survey sample reported that they had had conversations about the disease with other women.

RQ3: What emphasis do women place on personal, proactive breast cancer prevention information-seeking? Health information-seeking on the Internet was common among interviewed and surveyed women. However, breast cancer information-seeking, and particularly prevention information-seeking was less common. Few women interviewed said they had actively sought this information online but over one-third of surveyed women had done so.

RQ4: What do they think about the Internet? How do they describe the Internet's role or importance in their social setting or community? Internet use was commonly reported in the interviews and nearly two-thirds of surveyed women said they used the Internet during an average week. Surveys revealed that age, education and income levels were all correlated with the amount of time spent Internet. Interviewed women described a range of activities and

purposes for which they used the Internet, including communication, looking for information, and entertainment. Survey results showed that a variety of activities were well represented. Over 40% of respondents cited using the Internet for information-seeking, emailing, news reading, directions, assisting children with school work, and performing job searches.

RQ5: What do African-American women think about the Internet as a source of breast cancer information? For women who use the Internet for breast cancer information, how do they describe their experience? Although interviewed women reported low rates of breast cancer information-seeking, they said they frequently use the Internet for other health searches. When asked what would prompt the women to seek breast cancer information, the two answers were a family member's experience with the disease and a personal scare, such as a suspicious mammogram or a lump found in the woman's breast. These two prompts were the most commonly indicated reasons why the surveyed women who said they had looked for breast cancer information online initiated that search.

RQ6: What features or characteristics of the Internet enhance or deter women's experiences seeking breast cancer information? Again, few interviewed said they had searched for this information, so the survey was developed to include general questions about health information searches. Interviewed and surveyed women reported preferences for generic search engines, such as Yahoo and Google, for their health searches. Even though interviewed women were not asked to list every reason why they would use the Internet for a breast cancer information search, some of the Internet characteristics they mentioned liking were the convenience of using the Internet at home and at any time, the wealth of information available, and ease at which the information could be accessed. These answers were common in the survey responses, too. Reasons why interviewed and surveyed women said they would not use the

Internet for breast cancer information-seeking, even if they wanted information about breast cancer, cited physical access limitations. Surveyed women also reported that not knowing how to use the Internet would prevent them from using it for this purpose.

Although interviewed women were not asked to estimate or quantify their perceived risk of breast cancer, compared to other women their age, the women who did not have a family history shared that they did not consider themselves especially at risk for the disease.

RQ7: Among members of these two groups – African-American women with breast cancer family histories and those without them – are their reasons for using or not using the Internet more related to their beliefs about breast cancer or to their beliefs about the Internet? Beliefs about the Internet did not seem to influence women's searches for breast cancer prevention information. Prevention information-seeking did not seem to be related to trust issues about the Internet. Women interviewed did not search for this information because they did not think they needed it. Either the women believed they had all the information they needed about the disease or, not contradictory, they did not need to know about a disease that was unlikely to involve them. This view seemed to be associated with women's perception of breast cancer as uncontrollable and most likely to affect women with family histories of the disease.

CHAPTER 7 DISCUSSION

This chapter will put the study's findings into context. Included in this portion of the paper are several subsections: some main points and findings revealed by the study, important themes and answers to research questions, the model of variables that emerged from the study, comparison of results to those of previous research, study limitations, and suggestions for future research. Some leeching of future research into important themes was unavoidable due to relevance to those themes. Several findings that were extraneous to the research questions but relevant to the study's overall purpose of finding ways to reduce breast cancer incidence and mortality will also be discussed as part of the general themes.

The study examined two important yet constantly evolving subjects. Breast cancer, which many interviewed women said was once considered a death sentence, has been the focus of research and awareness over the years and has become much more survivable. The Internet is an innovation that is ever increasing its functions and range of users. When studied together, breast cancer and the Internet represent fertile ground for study but also present difficulties keeping pace with advancements in the disease's science and the technology's progression. However, by focusing on beliefs about the disease and about the Internet, as opposed to measures of accurate knowledge about the subjects, this study put the point of emphasis on the body of literature and health behavior theories that recognize that people's beliefs about health and taking health actions are important components of people actually adopting (or not adopting) a behavior.

Four main conclusions were reached. They are summarized here and then explained more throughout the rest of this chapter: family history was often cited as the main risk factor for breast cancer; women thought about breast cancer prevention in terms of secondary prevention and screenings; online health information-seeking was a common behavior among the women

but breast cancer information-seeking and prevention information-seeking behaviors were less common; and the study did not fully answer the question about the role of beliefs about breast cancer prevention and beliefs about using the Internet for breast cancer prevention information but it identified methods that might be used to answer those questions in the future.

First, family history of breast cancer was the most commonly cited risk factor for breast cancer among survey takers and interviewed women. Due to the open-ended question format, more about the relationship between beliefs about breast cancer risk factors and the women's perceptions of personal risk could be inferred from interviews than from surveys. Interviewed women, for the most part, seemed to believe they were at higher risk for breast cancer if they had a family history of breast cancer.

Proximity to breast cancer experiences was an important concept in the interviews. The difference in how the two groups expressed beliefs about breast cancer might be explained with a weather analogy: residents of Kansas know that hurricanes can be scary and devastating, but they do not feel the susceptibility or have first-hand experiences with the storms' impact that coastal residents have. Every woman in the interview believed that breast cancer was a fear-inducing disease, but the degree to which each woman thought she had reason to fear getting breast cancer varied, with higher risks expressed by the women who had family histories of the disease. Consistent with the weather analogy was the idea of breast cancer beliefs being influenced by proximity to the disease, either by having had a personal scare involving a benign lump or suspicious mammogram, or experiencing the disease vicariously through close female relatives.

Likely influencing the women's personal beliefs about breast cancer were the social environments where they engage and the generations to which they belong. This component also had a proximity element; instead of involving proximity to the disease in one's immediate

family, this latter type involved proximity to changes and trends in the way breast cancer is treated in society and scientific advancements in diagnoses and treatments. Specifically, descriptions of breast cancer spanned a spectrum from thinking death was the primary outcome at one end, to strong beliefs in early detection and survivability on the other end, with the middle of the spectrum representing the pivot point where women said they had associated breast cancer with death but now recognize awareness efforts and new medical techniques that can extend women's lives after diagnosis.

Although previously discussed research does point to a connection between family history and breast cancer risk, the ACS's data (2009b) show that women with family histories represent a relatively small percent of total breast cancer cases. These statistics represent women in general, not African-American women specifically. More research is needed to parse the influence of family history of breast cancer on personal risk of diagnosis in women of different ethnic groups. However, one study (Simon, et al., 2006) suggested that white women with family histories of breast cancer may have a higher risk of developing the disease themselves than do African-American women with this family history. Referring to the literature, the authors suggested that factors such as birthing patterns where African-American women on average give birth at younger ages than Caucasian women, may play a role in the smaller risks for African-American women with this history.

Second, discussion of prevention focused on secondary screenings for breast cancer. The NCI's Web site still describes prevention in terms of avoiding getting breast cancer (NCI, 2009b). Screening is the word used for mammograms, X-rays, MRIs, clinical breast exams, and other forms of detecting breast tumors. Both the NCI and the ACS frame primary prevention of breast cancer in terms of avoiding known risk factors. Those factors include tobacco use, obesity,

hormone replacement therapy (HRT), late childbearing, radiation exposure, and other potential risks suggested by research. The extent to which many of these and other factors may be avoidable varies and will be rather specific to individuals. For example, despite physical and financial obstacles, most women may have some control over their food and exercise choices, alcohol and tobacco use, and use of HRT. A woman's ability to become pregnant and the years when she begins and ceases menstrual cycles are less controllable. The lack of clear guidelines about what women can do, if anything, to prevent breast cancer, as opposed to things they can avoid to prevent the disease, such as not smoking, may impact their views about prevention and efficacy of prevention.

Third, use of the Internet for health information-seeking was rather common. However, the use of the Internet to look for breast cancer information – especially prevention information – was less common among surveyed and interviewed women. Interviewed women revealed that they are more likely to seek information about conditions that are affecting them personally or affecting a family member. The perception of low risk among women without family histories of breast cancer may reduce their interest in such information searches. From this, it is clear that the women's beliefs about their risks for breast cancer, as opposed to their beliefs about the Internet, influence their decisions to search or not to search for prevention information.

Fourth, the study's methods were insufficient for examining the kinds of content access issues presented in the paper's earlier chapters. Although not a listed research question, the concept of women's content access to the Internet and online information about breast cancer prompted and even undergirded much of the research. In other words, the study sought to look beyond the dichotomous states of physical access to the Internet – where the women either have or do not have access to computers with the Internet – that seem to be common measures of

Digital Divide issues, to explore the actual experiences of women who do and do not have the Internet. However, examining beliefs about the Internet in the surveys and interviews did not answer the larger questions about content access, the factors beyond having physical access to an Internet-connected computer that influence how women understand and make use of online content, and experience. Discussion presented later in this chapter addresses the limitations of the methods to answer content access and even health literacy questions.

Summary of Major Themes

One theme was that a woman's proximity to breast cancer influenced her beliefs about the disease, with interviewed women who had close female relatives with past breast cancer diagnoses filtering their beliefs through memories of that experience, and interviewed and surveyed women perceiving their personal risks based on family history. Women without the family history sometimes mentioned friends or extended family with breast cancer, but the women's descriptions and beliefs were based on more abstract or second-hand knowledge of the disease. Fear and death associated with breast cancer was sometimes cited, too.

Another theme was the tendency for women to think of breast cancer prevention in terms of secondary prevention and early detection. Most of the women reported having had at least one mammogram. Related was the theme of women's lack of knowledge about breast cancer. Interviewed and surveyed women overwhelmingly cited genetic family history as the number one risk factor for breast cancer, when age is a bigger factor.

The interviews revealed a theme that women did not perceive a need for breast cancer prevention information. This was largely because the women without breast cancer histories in their families did not think they were at risk for breast cancer or that anything could cause or prevent cancer, except in some cases, smoking and being overweight.

The theme of women tending to talk about breast cancer more if they had a family member who had experienced the disease came up in the interviews but was not found in the surveys. This chapter suggests future studies should revise survey wording for this question to see if and with whom women talk about breast cancer.

Both the interviews and the surveys revealed the theme of other diseases being more common, therefore higher priorities in the women's communities. In the interviews, disease priority related to observing how common the problem was in the community, not necessarily on the extent of outcomes from each disease.

An important theme from both study methods was that Internet non-use related to lack of physical access to the Internet rather than beliefs about the Internet being a good or bad source of information. Online searches for breast cancer and breast cancer prevention information-seeking may have been somewhat uncommon, yet most women who used the Internet said the medium would be a good source of that information, if the women had questions about the disease. Among those who had sought breast cancer information, prompts included having some other personal scare or a family member with the disease.

Model for breast cancer prevention information-seeking. Relationships between the study's major themes came rather clearly from the qualitative portion of the study but were more ambiguous in the surveys, a result that may be an artifact of the closed-ended questionnaire format that allowed no room to explore the meaning of women's answers. Given this, and the ability of the qualitative portion to explore these meanings, priority will be assigned to the interview findings.

Figure 7-1 shows a concise theory of characteristics and beliefs that the interviews point to as antecedents to using the Internet to find breast cancer prevention information for oneself.

These points, which are randomly ordered, are based on women's comments about why they looked for some health topics online, why they did not look for breast cancer prevention information, and what they believed about breast cancer risk and prevention. Each concept will be discussed in further detail later.

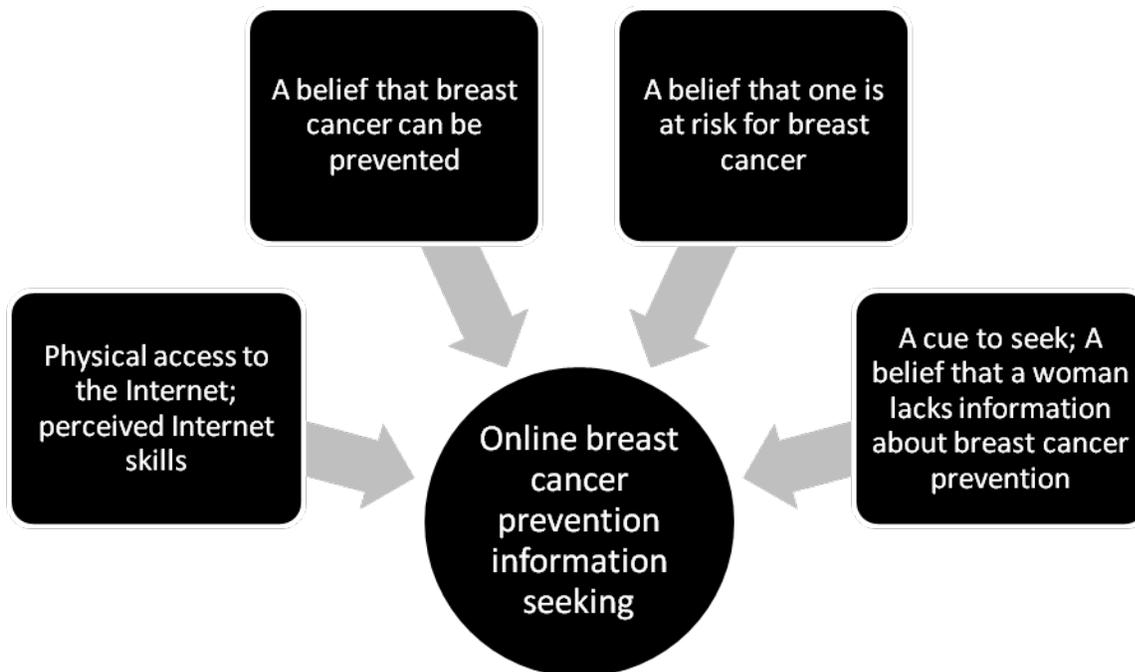


Figure 7-1. Antecedents for online breast cancer prevention information-seeking

Physical access to the Internet & perceived Internet skills. The most obvious condition for women to use the Internet for breast cancer prevention information-seeking is having physical access to the Internet. None of the women interviewed expressed any concerns about the medium or trust issues that they said would keep them from using the Internet for breast cancer information-seeking, although some women expressed a preference for physicians' advice. Instead, non-use of the Internet was related to lack of familiarity with the medium or not having a computer with an Internet connection.

One of the study's research questions asked if women's beliefs about the Internet or beliefs about breast cancer were related to use of the medium for breast cancer prevention

information-seeking. In the results chapters, the researcher somewhat dismissed the notion that not seeking prevention information was related to beliefs about the Internet as a source of breast cancer information. For women who used the Internet for health information purposes this description may be adequate. The relationship between beliefs and prevention information-seeking is less clear in the women who did not use the Internet for health information. The interviewed women who did not use the Internet attributed their non-use to logistical issues, such as lack of familiarity and lack of physical access, instead of trust or quality concerns about online content. However, lack of familiarity and access are actually beliefs about the Internet. At very least, these are beliefs about the utility or efficacy of the tool and women's abilities to use it. Although time and money are integral to the decision to use the Internet, the basic concept is one of cost-benefit analysis in economics. Even for a time- or budget-strapped individual, her view of the Internet as being a useful tool for her health, education, or children's future might incline her to make the technology investment at the expense of other items or activities. We saw this in Linda's case – the housekeeper who admitted to a limited income but thought the Internet was worthwhile for her children's sake. However, for simplicity's sake, this box in the model refers to physical access instead of beliefs about the utility of having physical access. The other interpretation will be further addressed in the future research portion of this discussion section.

A belief that breast cancer cannot be prevented. This theme was implied by the women's opposite reaction to questions about breast cancer risk and prevention. The participants thought that breast cancer risk was related to family history. Several women said they did not know breast cancer could be prevented, in a primary prevention sense of the word. In fact, most of the prevention answers were related to secondary prevention – prolonging life by detecting

tumors early through mammograms and other screenings. To some extent, breast cancer may not be avoidable for many women, but others may adopt healthy lifestyles and screenings to decrease their chances of developing, suffering morbidity-related effects, or dying from the disease. However, if a person does not believe that a disease can be avoided, she likely will not seek information about things she can do to prevent it or reduce her risk.

Preventing breast cancer was a concept associated with secondary prevention, a view that might be explained by the very commonly expressed thought that breast cancer risk is associated with family histories of the disease. Presumably this association is perceived as an inherited genetic risk. Despite ongoing research in the area of genetic engineering and modification, no studies were found to date that allow scientists to turn on or off identified genes such as BRCA1 and BRCA 2 that may lead to breast cancer. However, it is also important to reinforce the estimates that only 20-30% of women who develop breast cancer have a family history of the disease (ACS, 2009b). As inherited genes are seen as uncontrollable at the time of this research, women with the family history may think there is nothing they can do to prevent getting the disease if that is their genetic fate. Women who do not have the disease may perceive themselves as somewhat immune from breast cancer. The other potential interpretation follows the “out of sight, out of mind” axiom, where women who do not have experiences with family members with breast cancer just have not thought about the disease, much like people who live in the United States may not think about their susceptibility to diseases that affect people in other parts of the world. The corollary to this explanation would be that for women who have experienced breast cancer in their families, breast cancer is more present and impacting on their lives.

A belief that she is at risk for breast cancer. This theme crosses over the one about prevention beliefs. Women who thought breast cancer is completely (or mostly) based on family

history and who have no such family history may think they have low risks of the disease; whereas women with a mother, sister, or grandmother who developed breast cancer described the possibility of them getting the disease as likely or higher than normal. However, having had a breast cancer scare, such as a benign lump or an abnormal mammogram, may increase a woman's sense of proximity to breast cancer – hence her perceived risk – regardless of her family history.

A cue to seek information or a belief that she lacks information about breast cancer prevention. The first part of this theme, “a cue to seek,” represents an umbrella concept, comprising several possible cues. The second part, “a belief that she lacks information,” is also important and may or may not be conditional upon a major cue. This distinction may be unclear until examples of the various circumstances are described. First, cues to seek were mostly described in the interviews as personal scares, such as finding a benign breast lump or having a family member diagnosed with breast cancer. When a family member is diagnosed, the woman may seek general breast cancer information to help that relative with treatment decisions or support needs. She may also find her own risk schema is affected by the relative's diagnosis. If the woman has not felt at risk before, due to lack of family history of breast cancer, a close, maternal relative's experience could alter the woman's perceived susceptibility. If the relative is farther genetically removed – an in-law or a cousin, perhaps – and this diagnosed person also did not have a family history of breast cancer, the woman's association of risk with genetics may also falter as she sees that women without the history can get the disease.

The latter condition in the figure's box, “lacks information,” describes the condition that was not found in the interviewed women with breast cancer family histories. These three women believed they already had the information they needed to know; therefore these women might not

become breast cancer information seekers unless they decided, at some point, they lacked some information about the disease. They experienced the disease firsthand with their mothers and other relatives and reportedly absorbed information at the time. These women may feel that they already know what they need to know about breast cancer. This condition is important because a woman could meet all of the other ones – have Internet access, believe that breast cancer risk can be reduced through certain behaviors, and feel susceptible to the disease due to family history; however, if she believes that the information she received from doctors and pamphlets when her relative had the disease was sufficient, she may not believe she needs to actively seek more information. Two of the women in the interviews implied this much; they thought they knew what they needed to know about breast cancer. One of the women expressed a different view when she described a recent search for information about new technology for detecting breast cancer. Even though this example is one of secondary prevention, it showcases an important variable at play with women who have family histories – time since the relative’s cancer experience. Medical science changes rapidly. Women whose mothers or other family members had breast cancer decades ago might benefit from learning about advancements and new knowledge about breast cancer prevention.

Similarity to the Health Belief Model. The theory grounded in the qualitative data about breast cancer prevention information-seeking in women without the disease is a good fit to the Health Belief Model’s (HBM) concepts. The HBM is a framework for thinking about why people do or do not take actions to prevent diseases, based on their beliefs about the disease, their perceived susceptibility to the disease, and the weighing of the costs and benefits of the prevention (Janz, Champion, & Strecher, 2002). Even though the present study was not a theory-testing exploration, many of the HBM’s tenets were present in the data, including perceived

severity, perceived susceptibility and cues to action (See Table 7-1). One component of the HBM not specifically addressed in the model is perceived severity. The study did not reveal enough about how perceived severity might affect seeking. The study suggested that women do not rate breast cancer as a major concern in the community and that women may not seek breast cancer prevention information at high rates. However we do not know if the reverse would be true: if women do perceive the problem to be severe, would they seek information about the problem? Based on this lack of clarity, the researcher thought it premature to stress the condition in the model.

Table 7-1. Comparisons between the HBM and the study's findings

Health Belief Model tenet	Study's findings
Perceived susceptibility	Based mostly on the absence or presence of breast cancer in a woman's family history; to a lesser extent, based on personal scares, such as a benign breast lump or a suspicious mammogram
Perceived severity	Priority in community is seemingly based on how many people a disease affects, rather than the impact the disease has on the patients' lives; deserving more attention are beliefs about what happens to women who develop breast cancer because, even though participants sometimes associated breast cancer with death, they still did not express many risk-avoidance behaviors
Perceived benefits	Women ascribed positive outcomes to early detection, such as self-checks and mammograms. However, the view that breast cancer was related to family history of the disease may affect views about the benefits of primary prevention and seeking information about breast cancer prevention on the Internet.
Perceived barriers	Myths, lack of knowledge about breast cancer prevention; barriers to seeking information online include physical access issues
Cues to action	The woman having a personal scare or a family member developing breast cancer; some implied that news stories that stressed severity of a health problem or risk factors she had might make her seek out more information about the condition
Self-efficacy	No good measure about how confident women were to look for and find breast cancer prevention information

Despite some of the similarities in the HBM and the study's findings, one important distinction should not be glossed over: seeking breast cancer prevention information is not actually a form of prevention; it is an intermediary step for preventions such as diet changes, alcohol consumption reduction, and smoking cessation to occur. The prevention goals are those healthful lifestyle suggestions, and the behaviors are adopting those lifestyles, not attaining knowledge about them, which the Internet provides. The Internet may be a helpful facilitator of those behaviors, providing support from other women in online communities or providing tools for nutrition and exercise, but finding breast cancer prevention information is merely a step to the goal of adopting the behaviors.

On the flip side, the rise in health care consumerism (Calabretta, 2002; Keckley & Eselius, 2009) and empowered patients requires us to think more analytically about the role of information along the disease prevention behavior spectrum. While Internet information-seeking may not be a true health behavior in the vein of nutritional attainment or toxin avoidance, it may be becoming a bigger influence on many of the well-vetted health behavior theories. Where once information may have played a role in giving people knowledge about health topics and the media may have shaped views through coverage, the Internet as a form of mass media may do both of these things as well as serve as a support system, self-efficacy enhancer, and a maintenance tool. For example, another widely known health behavior model, the Precaution Adoption Process Model (PAPM), posits that people move through seven stages when approaching a health behavior (Weinstein & Sandman, 2002). In the first two stages, a person moves from not being aware of the health issue to being aware but unengaged by it. Proceeding from that point are the stages wherein people decide if they will act, how they will act, actually acting, and maintaining that action. Clearly the Internet has a potential role in changing

unawareness about breast cancer prevention into awareness through facts and explanations of the disease. Through many multimedia and interpersonal communication tools, a woman may also become engaged with the issue. Interactive features on the Internet may also serve as decision aids. For example, the National Cancer Institute has an online breast cancer risk assessment tool to help a woman estimate her own risk (NCI, n.d.). And a plethora of Web sites offer services to plan and track healthy lifestyle goals such as diet and exercise, which could be considered maintenance functions in disease prevention.

When electronic health records and personalization features become commonplace, more patient-specific online tools may give women opportunities to integrate multiple health functions into their health management. For example, the Department of Veterans Affairs (VA) already offers its health system patients the online portal, MyHealthVet, to perform general health information searches, access lab and test results, and manage prescription medications. Beyond the VA, more integration of personal health history with personal risk of diseases is a likely outcome of the available technology and trends in patient empowerment (United States Department of Veterans Affairs, 2005).

This paper offers no conclusions about the place of online breast cancer prevention information-seeking in contemporary health behavior theories and certainly does not argue that the two discussed here are the most appropriate models. More accurately, the study suggests that additional research is needed to understand the place of online prevention information-seeking in each theory, including those with strong social belief components.

Themes Unrelated to Research Questions

This study is intended as an academic exploration of the relationship between two theoretical models – the ecological model of public health and a new media model of access. However, the ultimate purpose of this type of research is to contribute to the reduction or

elimination of breast cancer disease burden. During interviews, women brought up topics that were unrelated to the project's research questions but that were, nonetheless, interesting and relevant to the overall effort of preventing breast cancer. For that reason, a few of the topics are presented here.

The first topic concerns knowledge transfer and communication between primary care physicians, patients and mammogram service providers about breast cancer screenings. Women in the interview without family histories of breast cancer reported low knowledge of breast cancer and their own risks, even though nearly all of them had received a mammogram in the past. Two women said they did not know how often mammograms should be scheduled, with one saying she thought her physician would tell her if her personal risk was high enough to require another mammogram.

Although women reported a trust in their physicians and sometimes a dependence on the doctors to tell the women what health tests they needed and diseases they might be at risk for, this dependence may present obstacles to educating women about breast health. Joyce described changes she saw in generations' approaches to health care seeking, saying:

You know, it's so different now. I was, the way I was raised, you go to the doctor every year for a checkup. When I was raising my kids, every year they had a scheduled time, "okay, I'm going to take you now to get a checkup." Now that they're grown, you know, my oldest son is 28, my youngest son is 24. They might go to the doctor if they're sick but other than that they're not going to go. So it's just the way you're raised different, I guess. You know, I was raised up like that...They don't think to go to the doctor to get a checkup every year or get their cholesterol checked, blood pressure checked. They just don't think like that.

While generational issues involving patients' views of sick and preventive care may exist, it is important to note that the medical community continues to debate the value of preventive medical care for otherwise healthy people. One particular study that caught the mainstream media's attention (e.g. Blue, 2008) was based on Mehrotra, Zaslavsky, and Ayanian's (2007)

study of preventive health examinations that showed routine, preventive medical office visits accounted for \$7.8 billion annually and a significant portion of physicians' time. Those who highlight drawbacks of annual physical exams as part of preventive health care suggest that the financial costs to patients and the health care system outweigh the benefits, suggesting that such routine care has not been shown to dramatically improve outcomes (Gordon, Senf, & Campos-Outcalt, 1999). However, other researchers have found positive benefits of preventive health exams, including alleviating patient worry (Boulware, et al., 2007). In the case of mammography, Mehrotra and colleagues (2007) found that these preventive screenings and education were taking place largely outside of regular physical exams. The debate about periodic physical exams efficacy is significant to this paper only in that if other women like the few interviewed here rely on interactions with physicians during periodic exams to prompt their breast cancer screening behavior, and that health care venue may be assigned diminished value in the future, other interventions must reach women with breast cancer screening education. Also, if women perceiving themselves at low risk for breast cancer wait for physicians to initiate mammography discussions, where does that leave women who only go to the doctor when they are ill? This area remains fertile for more research into the prompts that may lead women to adopt screenings.

The survey instrument intentionally lacked the precision needed to shed light on mammogram frequency because, again, secondary prevention was not the main focus of this study. However, future research into general breast cancer prevention behaviors should endeavor to flesh out issues of perceived adequate prevention (getting one mammogram at age 40 but no more after that age) versus medically recommended prevention (including regular mammograms,

clinical breast exams, and/or whatever physicians recommend for each woman based on her risk factors for breast cancer).

Another common theme among the women who had had past mammograms was the importance of free screenings as part of health fairs or workplace initiatives. When asked why they had received mammograms when they did not think they were at risk for breast cancer, many women said the reason was that the mammograms were free. One woman who was concerned about promoting health in her community said that she wished more mobile mammograms and free, convenient screenings were made available to women in poor neighborhoods.

States where the interviews and surveys were conducted offered free or low cost mammograms through the National Breast and Cervical Cancer Early Detection Program to women meeting certain eligibility standards, including income, insurance status, and age (CDC, 2009b). Details of the offers vary somewhat by state. For example, one of the states in the study area offered the screenings for women older than 40 whereas the other state set the minimum age at 45, unless the woman had symptoms. This program means that women who were financially unable to afford mammograms may be able to get one for free, reducing costs as a barrier to the screenings. In addition, positive test results and treatments necessitated may also be covered through the program.

Among the most useful exercises the researcher engaged in post-data analysis was one of semantic dissection of the study's objectives and data collection tools' words. Several discussion points emerged from considering the study's findings and thinking critically about the nuanced meanings in them. Posed as questions, some of the points included the following:

What do we consider breast cancer prevention information-seeking? Does it require actually wanting to know what prevents breast cancer and framing Internet searches in those terms? Or can a person's mere search for topics that might prevent breast cancer outside of that context constitute a search for prevention information?

The distinction is so subtle that these words likely do not convey the difference and an example is required. In a case of the former, a woman might go to the Internet with questions about preventing breast cancer, using those search terms. During her search, the woman might discover that scientists encourage women to eat healthfully in order to prevent many different diseases, including breast cancer. However, in the second case, a woman could look for information about other topics, such as diet, exercise, smoking cessation assistance and alcohol consumption reduction. A woman may look for information on those topics for reasons other than cancer prevention and, by enacting certain behaviors based on the found material, may reduce her breast cancer risk without that having been her purpose. The distinction is one of intent. By looking for and adopting healthy lifestyle behaviors in effort to be physically fit, a woman may find advice about including a variety of fruits and vegetables in one's diet and being physically active. These are the kinds of diet and exercise advice experts recommend for reducing cancer risk. Yet the information she finds may not make any connections to cancer reduction benefits.

While this example seems like a minor semantic issue, it had bearing in the study's interviews. Several women said they used to the Internet for healthy recipes, weight management, and to find out the caloric and nutrient contents of foods. Joan, the woman who had breast cancer in her family and was determined to stay healthy herself, mentioned using the online diet plan site, Spark People, for nutrition management. The question arises about how

controllable risk factors for breast cancer prevention, including diet and exercise, not smoking, and drinking alcohol in moderation, should be emphasized and branded as breast cancer prevention behaviors or co-branded as good health lifestyles that reduce the risks of a wide range of diseases. As previously mentioned, science offers no guaranteed ways to prevent breast cancer, except prophylactic surgery in some cases, (especially since two of the biggest risk factors – being female and aging – are uncontrollable); however, these healthy lifestyle behaviors may be of some value in breast cancer prevention efforts.

How important are beliefs about online health information-seeking? How do beliefs about this relate or translate to health outcomes? This line of questions emerged from listening to women describe their health information-seeking processes, including how they decide if a source is good. Constituting one of the extraneous study themes alluded to earlier was this idea of Web site evaluation approaches. In addition to evaluating based on source credibility, which was uncommon, and based on consensus of information across multiple Web sites, one method employed by the interviews was evaluation based on how well information fits the situation. All of the interviewed women turned to generic search engines such as Google and Yahoo to search for health information, and the surveys pointed to similar reliance upon these online tools. Because the interviewed women reported only searching for health topics that were affecting them or their family members, they approached searches with specific questions in mind, such as: “What are the side effects to this medication the doctor prescribed for me?” and “What treatments are available for this condition affecting my husband?” Not surprisingly, the women considered a Web site valuable to them if it answered their questions or helped them understand a topic better by using easy-to-understand terminology. Betty and Rachel offer explanations of a major evaluation criterion – good informational fit to one’s information needs.

Betty said:

‘Cause usually if I have time I’ll sit there and kind of speed-read through it and say ‘Nah, that’s not the type of information I’m looking for,’ and I’ll go back to the list of things and click another one and look at it. ‘Yeah, that’s more what I’m looking for.’

Similarly, Rachel said she enters her keywords into a search engine, generates hits, and “Um, a lot of times I just go through each one. Or if, um, the exact thing came up, I would just click on that.” When asked what she meant by “the exact thing,” Rachel said it was the answer to the question she had or what she wanted to find.

The interviewed women who searched for online health information reported general confidence in their ability to find answers to their questions. However, their confidence stemmed from finding answers to their questions, not necessarily from finding accurate answers to their questions or from accurately interpreting the health information on the Web pages. The sites that satisfy their curiosity and answer their questions may not be medically accurate and could even cause the women to make decisions that are not in their best interests. Returning to the concept of patient empowerment, women who find inaccurate information about breast cancer may feel a sense of empowerment, but lacking true facts and explanations, they are not fully able to make informed health decisions.

The new media model described at the beginning of this paper posits that one’s ability to benefit from online health information is a multi-component determination, meaning here that a person with low health literacy may feel just as confident as a person with high health literacy that she can find, understand and can implement in her life the information on Web pages. However, the two people’s actual benefits may differ greatly. Beliefs about the Internet and self-efficacy of Internet skills have some importance in health information-seeking, likely as a type of initiator of the behavior; however, future research must focus on other measures, such as those described in a non-exhaustive list in Table 7-2.

An earlier chapter posed the possibility of using a new media model of access (Newhagen & Bucy, 2004) along with the ecological model of health to conceptualize a research agenda for health information-seeking. Even though this study did not provide clear direction for this, or even speak to whether or not such a conceptualizing would be appropriate, the possibility remains. With a clearer picture of the appropriate measurements (e.g. beliefs, attitudes, and behaviors about breast cancer and the Internet; physical access, user demographics, and health literacy), it may be useful to understand how factors influencing Internet use and benefit complement or are distinct from factors influencing health prevention behaviors. Thinking in these terms may help identify behavioral interventions and opportunities to better utilize technology to promote disease prevention in different populations. If this discussion seems too abstract, consider one shared domain of health behavior and Internet use: self-efficacy. What if a woman has low self-efficacy for enacting preventive health behaviors but high self-efficacy for Internet use? Could this woman's high self-efficacy for using the Internet, with its interactivity and multiple opportunities for social modeling interventions, increase her self-efficacy to adopt prevention behaviors? This study can only be used to speculate that there might be opportunities to explore relationships between health status and behaviors with Internet use and benefits of use in order to maximize effectiveness of conveying health information to the public and subpopulations. Doing this may yield a more interesting and more comprehensive body of literature about Internet use than simple analyses of demographic information as it relates to health information-seeking. It should extend beyond describing how often and for what purposes people of each age category, race, income level, and other demographic variables use the Internet.

Table 7-2. Potential measures in future research about Internet health information-seeking and health prevention

Health Measures	Internet Measures
<ul style="list-style-type: none"> • Individual characteristics, including health status, socioeconomic indicators, demographics, family history of the disease, insurance coverage, health literacy • Individual beliefs, attitudes, and behaviors about a health condition, including self efficacy to prevent a disease • Social influences of beliefs, attitudes and behaviors, including interpersonal networks and group membership and the importance placed on health behaviors by a person’s social circle • System level measures, including physical access to health services; system racism • Ecological studies, including epidemiological explorations about disease incidence and prevalence, and prevention behavior, and statistics about health system access and use • Health literacy as it relates to the ability to successfully understand condition information and the extent to which this literacy relates to successful outcomes of preventive behavior adoption 	<ul style="list-style-type: none"> • Individual characteristics, including socioeconomic indicators, demographics, computer literacy, literacy, physical and cognitive abilities • Individual beliefs, attitudes, and behaviors about the Internet, including self-efficacy to use the Internet • Social influences of beliefs, attitudes and behaviors, including interpersonal networks and group membership, and the importance placed on Internet use by a person’s social circle • System level measures, including physical access to the Internet by demographics • Ecological studies, including surveys of Internet use and health information-seeking behavior • Health literacy as it relates to the ability to successfully understand condition information and the extent to which this literacy relates to successful outcomes of preventive behavior adoption

This future research needs clear definitions of what the ultimate measure of information-seeking is and which other measures are important or superfluous to the goal of the Internet serving as a tool for disease prevention. Perhaps the ultimate measure is translating online information into prevention outcomes. Included among needed future research are studies comparing perceived understanding of online health content and accuracy of that understanding. The concept of this gap between perceived and real understanding is already considered in clinical settings, where providers are encouraged to explain health instructions to patients and have the patients repeat those instructions in their own words, to ensure the patient interpreted directions as the provider intended (Williams, Davis, Parker, & Weiss, 2002).

Do women’s perceptions of family history equating to breast cancer risk necessarily refer to inherited genes? Only during final analysis did the researcher consider that her interpretation of the women’s belief that family history is the same thing as hereditary genetics might be shortsighted. Although this interpretation seems most likely, based on context in the interviews, it is possible that the women were referring to families living together in the same environment, breathing common air, drinking water from the same source, and eating the same foods. After the interview ended, one woman pondered aloud if there might be something in the environment that was causing her family to be disproportionately affected by breast cancer. The researcher had prior knowledge that the woman’s community was home to a Superfund site and that locals sometimes expressed concern over what they perceived to be clusters of several health conditions in the area.

No other interviewed women mentioned this environmental possibility. Nevertheless, several survey questions were designed to further explore beliefs about breast cancer origins, including separately listed “family history” and “environment” items. As reported in the results section of this paper, family history was much more frequently marked than environment, implying that the women saw these as distinct risk factors.

Comparisons of study findings to previous research. The study’s attempt to incorporate and build upon the rich literature about African-American women’s beliefs about breast cancer necessitates a review of what the research revealed compared to previous scholars’ research. Where Moy and colleagues (2006) had found that African-American women do not talk much about breast cancer, this study’s survey found that 78% of the respondents said they had spoken to another woman about breast cancer.

Another finding compared with Moy and colleagues' research was the priority placed on other diseases in the community over breast cancer. Both the surveys and the interviews revealed that problems such as high blood pressure and diabetes were more common in the women's communities; therefore those conditions were considered bigger problems by the women. The interviewed women said that proximity to a health condition influences how they talk and seek information about it.

While the study did not specifically explore barriers to mammogram use, the interview participants' frequent mention of worksite programs and mobile mammography services is interesting in light of Powell and colleagues' (2005) finding that lack of time for mammograms was a major barrier to having the screening. For most of the interviewed women it appears that time was not a barrier because they were offered convenient mammograms as part of workplace and community wellness initiatives.

Several findings relate to studies in the literature about information-seeking and Web site selection. First, Kind and colleagues' (2005) found that many people who did not have computers and were not familiar with the medium were still interested in learning to use them. The current study did not explore this concept, but it is complemented by the earlier research that implied people's non-use of computers was due more to physical access and skill deficiency than to disinterest in using the technology or beliefs about the medium. Second, many of the Web site credibility evaluation concerns raised by other researchers (e.g. Bates, Romina, Ahmed, & Hopson, 2006; Eysenbauch & Köhler, 2002) were raised by this study. Even though the study did not focus on processes by which women judge Web site credibility, the interviews suggested that women had not had training in evaluating sources of online information.

Third, the effect of family members' experiences with breast cancer on prevention seeking was not clear from the study. Matthews and colleagues (2002) had found that emotional issues experienced during relatives' cancer experiences sometimes prevented women from searching for cancer information. None of the interviewed women cited this as an obstacle. The women did not say it was not an obstacle; instead they just attributed non-seeking to other factors, such as believing they already had enough information about the disease. However, the study did not attempt to measure relatives' outcomes from breast cancer.² Perhaps women whose mothers, sisters, or grandmothers survived the disease would have different beliefs about seeking breast cancer information than women whose relatives died from the cancer.

Practical Implications of the Study

One of the purposes of studies like this one is to apply what is learned from the research to health interventions. The mortality rate disparity between African-American and Caucasian women suggests that interventions for breast cancer prevention should remain a priority. Based on this study's research, health organizations seeking to encourage primary or secondary prevention among African-American women should stress that women are at risk for breast cancer even if they do not have a family history of the disease. Also, the study suggests a need for more education about mammogram frequency. If a public service announcement or other communication campaign were designed to address these issues, that message might incorporate information about how to find mammography services, including availability of low or no-cost mammograms in each state.

² This would have been a difficult measure in interviews and certainly in surveys. The interviews revealed that the women's self-reports about their relatives' causes of deaths may not be reliable measures of actual causes. For example, one woman said her mother did not die of breast cancer; rather she died when the cancer spread to another organ. More than likely the cause of death would have reflected the original site, the breast. Despite this inconsistency, studies of women's beliefs prompting or discouraging information seeking could use perception of cause of death as an appropriate measure.

Intervention planners seeking to use the Internet for breast cancer prevention education and promotion should anticipate that women are online health information seekers but may be unlikely to seek out breast cancer prevention information unless they perceive themselves at risk for the disease. An effective communication campaign incorporating the risk message described above may be a cue for women to seek breast cancer prevention information on the Internet. However, the intervention should put effort into incorporating a campaign Web site into promotion messages so the women viewing or hearing the campaign will know where to go for more information. Unless the women are directed to the campaign URL, they may find Web sites through generic searches that have low quality, inaccurate information about breast cancer prevention. Intervention planners should think of ways to increase the likelihood that women will remember the site URL. A short or memorable site name is one possible way. Incorporating the Web site on promotional materials given to women at health fairs is another way.

Study Limitations

As already stated, this project emphasized the qualitative portion of the study, which describes meaning as resting with the participants instead of the participants' meaning representing other women. The survey in this study, although a typically quantitative method of exploration, was ruled by the same interpretation of meaning that applied to the qualitative stage; namely that the survey results were not intended to represent other African-American women in the general public. Even though the results included some statistics appropriate to larger sample sizes, significance and other measures discussed in the findings section are not to be treated as generalizable to the population. The results attempted to approximate beliefs and behaviors of only the women in the group of 160 participants, constituting a non-random sample with inherent self-selection biases. For that reason, the survey could only be used to enhance inferences made from the qualitative portion and to generate questions for future research.

This study is not limited by the qualitative methods employed. Rather, our ability to generalize beyond the participants is inconsistent with the method. Our ability to see how well the results represent other women and what significance the findings have beyond the study is restrained by the method. Therefore, future research might seek to replicate this study with the existing methods as well as complement the study with other methodological explorations.

The first study limitation from the interviews relates to the women's ages. The results of interviews may have been different if older women had been included. Despite eligibility extending to women in their early to mid-sixties, the oldest woman interviewed was 56. The study's age parameters were designed to cover two things: women who were within the ages of mammography screening recommendations and women who might be targets of new media interventions for breast cancer prevention. There are two ways to look at this study; first for its potential to add to the body of research on the topic and second, for its practical importance. To address the first aim, stratification by age categories would have been necessary and results from interviews within each grouping might have yielded interesting insights into similarities and differences in Internet use by older and younger women. However, the latter interpretation seeks to answer questions of how best to communicate messages to women through the Internet. From a practicality standpoint, any interventions directly resulting from this study would take several years to implement, making women in their fifties and younger more relevant research subjects. In other words, if women closer to age 65 had been included, they would be over the age by the time any resulting project began. Although the study's parameters included women up to age 65, the purpose of this range in the qualitative study was not to look for similarities and differences between the ages, only to set an upper bound for interviewed women's ages not to exceed. It was thought that women older than age 65 might not have had as many natural opportunities to use

the Internet in their jobs and life, as the Internet diffused somewhat recently. Future studies should specifically examine age cohorts and Internet use, asking more sophisticated questions about how women in each age group use the Internet and how each group might be targeted with breast cancer prevention interventions. For example, opportunities may exist for social marketing and viral marketing of breast cancer prevention messages for younger women but those methods may not effectively reach older women.

Another limitation that might be overcome with additional study is the recall bias in asking women to remember details of the last time they used the Internet for different purposes. While the Internet users were able to give examples, such as looking up information about a prescription medication, they often had difficulty remembering their search strategies or the Web sites they used. One interpretation of the latter might be that the women chose sites that popped up near the top of the search engine results, as is consistent with the literature (Eysenbach & Köhler, 2002), but it is also possible that they used a more complex method for selecting Web sites. Several study designs might compensate for this recall issue. Future research should include studies using a “think-aloud” protocol or another form of audio recording wherein the participants are asked to do specific tasks or recreate a past search and explain to the researcher why they made online decisions at each step. Another possible study design to address this recall issue might be incorporation of a log or diary for women to record details of future online health information searches or using a keystroke capture program to record such searches, with women’s permission. However, these methods – and even the question about how women might search for breast cancer prevention information – are not directly related to the present study, which sought to learn first if women even used the Internet for prevention information, and if they did seek this information, why and how they did it. As the first condition was rarely

satisfied in the interviews, questions about search details were hypothetical and of proportionately less value to the study.

Other limitations to the survey include the inability to glean much from yes or no questions about topics like health insurance and mammogram use. Having health insurance does not mean a woman is fully insured. In fact, health insurance studies often refer to a middle class of underinsured individuals (Kaiser Commission, 2002; Monheit, 1994). The survey did not fully assess a woman's access to health care, limiting the ability to make analyses based on that variable. Adding more questions about previous health care system experiences, the type of health insurance coverage held, and the frequency of mammograms might have enhanced the study and should be included in future studies. However, analyzing mammography and health care access was not the original goal of this study, nor were those topics specifically related to research questions. More in-depth explorations of mammography beliefs were inconsistent with this project's aims but certainly should receive continued research focus, given how few women described topics related to primary prevention.

Another limitation identified during the survey analysis stage was the low consistency of the scales adapted from Champion and colleagues' (2008) mammography belief scales. Mammography beliefs and beliefs about breast cancer prevention and information-seeking are clearly different concepts, although they may be quite related. In addition to measuring different concepts, the question format and the categorization of the original items were modified in this study. These alterations may account for the low reliability found in the present study's scale questions. This study was exploratory and intended to measure many beliefs and factors related to breast cancer prevention beliefs and Internet beliefs, not to develop a testable scale for beliefs about using the Internet for breast cancer prevention information. However, future studies should

endeavor to create more scales directly examining how beliefs about breast cancer influence breast cancer information-seeking.

The survey and interviews both were intended to explore if and how African-American women talked about breast cancer and its prevention. One limitation of the methodologies that was revealed by the relatively high number of women reporting that they had talked to someone about breast cancer was that the nature and frequency of those conversations are unknown and not measurable in the present survey. The surveyed women may have construed the questionnaire question's meaning to include comments with medical professionals about the disease as opposed to strictly dialogue with friends and family members. The interviews implied this interpretation as several women said the topic of breast cancer does not come up in their social circles, yet the women mentioned receiving mammograms and having interactions with medical doctors about breast health that would technically qualify as talking about breast cancer. Future studies using surveys to assess how women talk about breast cancer with other women should address this limitation by describing contexts of conversations. For example, women might be asked if they had ever talked to a female friend about having a mammogram, or if they had discussed primary prevention of breast cancer with their physicians. Surveyed women might also be asked to select from a list of breast cancer topics (such as nutrition as a form of primary prevention) they discussed with family members and friends and medical professionals. Distinctions such as these would help researchers understand whether women are having casual, interpersonal conversations about breast cancer or if dialogue is confined to medical offices.

Mammogram use is another question with limited inferential opportunities. As the interviewed women implied, knowledge about the proper use and frequency of mammograms may be low. Surveyed women may have received one mammogram in their lives but not regular

screenings, every one to two years, as guidelines recommend (NCI, 2002). Future surveys could ask women how many mammograms they had had since they turned 40. These answers could be compared to the women's self-reported ages to estimate frequency of mammograms in the sample. Although the survey was not primarily about breast cancer and prevention knowledge, a question asking women how often they thought women over 40 needed a mammogram might reveal interesting findings, especially when considered alongside answers about the women's mammogram frequencies. If a 50-year-old woman believes one mammogram at age 40 is sufficient screening for breast cancer, and she reportedly has had only one of these tests in her lifetime, then her perception and behavior are seemingly consistent. However, if another 50-year-old woman believes mammograms should be performed every one to two years but she has only had one of the screenings, then other factors may be influencing her prevention behaviors. Barriers such as lack of insurance, inconvenient mammography centers, and other obstacles might be identified.

Another limitation involved the relationship between women perceiving problems other than breast cancer to be more widespread in their social group and perceiving themselves to be at risk for those conditions. The study did not address whether perception of other diseases as more common or higher priorities is an actual barrier to breast cancer prevention. It also did not determine whether women's perceptions of personal risk of diabetes, heart disease, high blood pressure, and the other "more common" diseases reflected the priority ranking they assigned to each condition. This issue might be addressed in future research by using the list of problems found in this survey and including scale beliefs about susceptibility to or risk for each of the health conditions. For example, the Likert scale item asking women to think about their personal risk of developing breast cancer compared to risks faced by other women their age could be

reworded to ask women about their personal risk of developing high blood pressure, HIV/AIDS, diabetes, and other diseases. Analyzing results of the women's rankings of priority health problems with the women's perceived risk of those conditions might reveal more about how the women see their own health risks as similar to or different from those facing their communities.

Future Research

Among the many questions that should be addressed in future research is, "What is an appropriate cue to action for a woman to seek breast cancer prevention information?" In the absence of family histories of breast cancer and personal scares with the disease, what mass media, clinical intervention, or interpersonal cues might prompt women to reassess their risks of breast cancer and their needs for information about the disease? The cue question is important because the study found that women who do want health information are relatively self-directed in their searches for answers to their questions.

In the area of breast cancer prevention, we must determine what the potential cues are if we want to trigger this information-seeking. Several of the women mentioned having seen something about breast cancer in the media, but they could not recall the stories and said they did not seek out additional information about breast cancer after seeing the stories. At the same time, most of the women in the interviews who did not have family histories of breast cancer perceived their risks for the disease to be low.

The interviewed and surveyed women focused on tangible risk factors – namely heredity, smoking, and diet – that could be assessed by looking no further than one's immediate family and one's own behaviors, as opposed to environmental and other factors. This implied that prevention education must include risk education that extends farther than these three factors to show that all women are potentially susceptible to breast cancer; therefore the woman being educated is at risk. Given the interviewed women's reliance on their physicians for answers and

direction about their health, primary care offices may be good opportunities for prevention education. However, many potential types and sources of cues should be developed and tested with a variety of research methods, including experiments and more qualitative studies.

Somewhat related to office-based intervention research is the opportunity for future exploration of how primary care doctors and radiologists/breast cancer doctors communicate and how they see each other's role in the process of patients' breast cancer education. Do primary care physicians expect they can promote mammograms to their patients at age 40, even scheduling appointments for their patients, but expect the mammogram clinic to take over from there and remind women to get future screenings? What happens, then, to women whose mammograms are conducted in more general radiology settings rather than those specializing in mammography?

Another line of research should focus more on comparing women's perceived beliefs about the Internet with their Internet skills. A key tenet of the new media model of access that inspired part of this study is that all access is not equal access. Two women with the same computer, Internet connections, reported confidence in online skills, and health questions in mind may have very different experiences in their health searches, depending on how well they actually navigate through Web sites, evaluate source credibility, and understand the often complex language on health Web pages.

This concept of content access has at least two implications and interpretations for future studies. The first interpretation remains on the personal belief and attitudinal level, with studies of women's perceived Internet skills, perceived utility of the medium for health searches, and related concepts. The second, more interesting line would focus more on outcomes than perception. This area would fall under the general health literacy heading, which spanned both

Internet and health measure columns in Table 7-2. For example, for women who want to find out more about taking primary prevention steps to avoid breast cancer – such as eating healthfully, limiting alcohol consumption, and exercising – how well are they able to find scientific consensus information about those topics versus finding Web advice they believe is good but which lacks scientific merit? When women want to find out how they can get a low-cost mammogram, can they find that information? Basically, is the information, if acted upon, likely to help the woman’s efforts to prevent or detect breast cancer early or is it merely giving her a sense of assurance? Although the present study focuses on beliefs, the Internet as a health communication source must either incorporate a behavior change function, such as a woman acting on advice about tobacco use cessation or adopting screening behaviors after she reads about prevention on a Web site, or be integrated into a larger health education strategy that ultimately is concerned with healthy behavior adoption or changes.

Other Web-specific future research may include experiments to find out what African-American women want in a Web site about breast cancer prevention and what presentation most effectively leads to learning. Also, explorations into how Web sites may be designed for women of many levels of Internet expertise may be useful. Perhaps most interesting would be research about how to incorporate Web sites about breast cancer prevention into clinic visits, such as in the form of an information prescription. Ritterband and colleagues (2005) said information prescriptions are opportunities for clinicians to direct “patients and their families to Web sites that contain information that is of high quality, appropriate to their condition, and consistent with their clinician’s approach to treatment,” in hopes that patients will benefit from the Internet’s advantages (e.g. frequently updated information) without choosing and relying upon inaccurate or poor quality information (p. e643). The interviewed women reported that they trust their

physicians and prefer information from that source. Integrating breast cancer education at that site might help guide seekers to credible sources of information and serve as a cue for the women to think about prevention when ordinarily they would not.

An important reason for studies such as this current one is to account for and try to correct disparities in health outcomes. Inherent in the research questions is the speculation that women of diverse racial and ethnic groups that experience different breast cancer outcomes have unique and multiple obstacles to getting the health care and education needed to prevent or detect breast cancer early. Some of these barriers may exist on the individual level, cultural, and system level. Therefore future research examining Internet and breast cancer beliefs should continue to look at disparities, considering women in general but also women who may have unique issues with technology and the health system. For example, women with low English language skills may face content access issues if Web pages are not available in the women's native language or are written at high reading levels, and these women may also face health system access problems and culturally-insensitive experiences with health care.

This point about cultural sensitivity recalls the literature about tailored health messages discussed in Chapter 2. In the study's survey, 64 women said they would prefer Web sites about breast cancer that were specifically for African-American women whereas 110 said they would prefer sites for women in general and 36 said it would not matter to them. As the statistics suggest, this survey item was of limited use due to women selecting more than one option (for a total of 210 answers representing 160 respondents), and several explanations exist for the observed greater preference for general audience Web sites. Two possible explanations include respondents' perceived social acceptability of a race-neutral answer and a distrust of race-

specific health information. Yet race-specific information was a very popular area of interest women noted on the survey.

Several interviewed women responded to questions about whether they would want breast cancer information Web pages with content tailored to African-American women by saying no, “a breast is a breast.” However, these women, and those surveyed, also said they might be interested in reading whether or not African-American women were differently affected by breast cancer than white women.

This area of discussion about preferences regarding health information tailoring is interesting in light of research suggesting that tailored information is more effective. The survey’s wording limited the utility of these questions about race-specific breast cancer information tailoring, and the sample size was too small to infer much from the statistics. However, these limitations do not preclude conjecture about the findings and future research. Among questions that arise include the extent to which women are consciously aware of information tailoring in health pamphlets and other communication materials they receive and how cultural tailoring fits into the Internet information-seeking experience. The latter, more ambiguously expressed question relates to the study’s findings (and confirmation of previous research) that women rely on generic search engines for health information searches and that they typically select from the first Web sites the search yields. African-American women conducting a simple search with the keywords “breast cancer” are likely to find general audience breast cancer resources among the initial hits. This likelihood is due to search engines using formulas that rank site popularity and produce the most popular links among the first sites in search results. Given that African-American women are a minority, it is logical that Web sites

focusing only on African-American women and breast cancer would not be among the most popular sites for general breast cancer keyword searches.

The Internet allows us to streamline the information we want – RSS blogs, subscriptions to newsletters, and such – so that even though it offers opportunities for exposure to many different topics, we still have many options to avoid the information we do not want or do not feel is relevant to us. Joyce’s description of an online pharmacy information subscription is a good example of this. She subscribes to an electronic newsletter. Even though it offers nutrition, exercise, and other prevention tips, Joyce specifically mentioned that she received information about her medications. More information may have been available. She may even have read it. But she remembered that the information was about her medication. The issues of proximity (currently experiencing a condition) and perceived risk likely influence whether or not a woman is attuned to these other pieces of information. Future research must incorporate what women believe about disease, how they use the Internet, and what opportunities might exist to use the Internet to activate potential health information seekers, not just anticipate seekers’ visits to health Web pages.

APPENDIX A
INTERVIEW PROTOCOL SUBMITTED TO THE INSTITUTIONAL REVIEW BOARD

UFIRB 02 – Social & Behavioral Research Protocol Submission	
Title of Protocol: African-American women’s beliefs about the Internet as a source of breast cancer prevention information	
Principal Investigator: Heather M. Edwards	UFID #:
Degree / Title: PhD candidate Department: College of Journalism & Communications	Mailing Address: Email Address & Telephone Number:
Co-Investigator(s):	UFID#:
Supervisor: Kim Walsh-Childers, PhD	UFID#:
Degree / Title: Professor of Journalism Department: College of Journalism & Communications	Mailing Address: Email Address & Telephone Number:
Date of Proposed Research: August 2008 – August 2009	
Source of Funding <i>(A copy of the grant proposal must be submitted with this protocol if funding is involved):</i> N/A	
Scientific Purpose of the Study: The study seeks to understand why African-American women use or do not use the Internet for breast cancer information. The project’s goal is to bridge gaps in the literature about the breast cancer experience in African Americans and Internet use by African Americans. A more important, applied purpose of the study is to better identify potential opportunities and obstacles for using the Internet as a breast cancer prevention promotion tool.	
Describe the Research Methodology in Non-Technical Language: <i>(Explain what will be done with or to the research participant.)</i> Women who respond to the flyers will be asked a few screening questions to determine if they qualify for the study. The questions include age, self-identification as an African-American woman, personal history of breast cancer, a mother, sister or daughter with a breast cancer history, and Internet use. Eligible women will be interviewed for 60-90 minutes. They will answer questions and talk about their opinions and beliefs about breast cancer, breast cancer prevention, the Internet, and using the Internet to find information about breast cancer prevention. The researcher will pose questions from the interview guide (attached). The sessions will be audio recorded for data analysis, with the women’s permission and with the assurance that the researcher will not use the audio file in a way that compromises confidentiality. After the principal investigator’s dissertation based on the study is complete, she will destroy the recordings.	

Participants will be asked to complete a short questionnaire before the interview to provide the researcher with descriptive data about the participants and to facilitate conversation about the topic. Included will be questions about their education level, income, church attendance, Internet use, media use, self-described health status, and questions consistent with the interview guide's topics. The women will be told that they don't have to answer any question they don't want to answer.

The qualitative nature of this study does not allow the researcher to set a participant sample size, but it is expected that no more than 100 women will participate in this phase of the study.

Describe Potential Benefits and Anticipated Risks: *(If risk of physical, psychological or economic harm may be involved, describe the steps taken to protect participant.)*

Minimal physical benefits or risks are anticipated. The participants will not be breast cancer patients or survivors; therefore they won't be asked to disclose personal medical histories. However, they may have close friends and family members who have experienced the disease. Talking about breast cancer may be emotionally difficult for some women, both because of mortality issues and the personal nature of the disease. Women will be told upfront what the general purpose of the study is and will be able to opt out of the focus groups and interviews before and at any time during the sessions. Local counseling resource information will be available for women who may express emotional distress, such as pain associated with experiencing the illness or death of a loved one.

Describe How Participant(s) Will Be Recruited, the Number and AGE of the Participants, and Proposed Compensation:

Participants for the interviews will be recruited in several ways. First, members of community organizations, such as churches and health-related interest groups, will be contacted for help recruiting participants. These individuals will be asked to place fliers advertising the study in places where potential participants might encounter them and also to personally tell women who might be interested in the study's subject about the opportunity. The ad may also be e-mailed to key informants. Second, the researcher will seek to attend meetings of organizations with potential participants and announce the study at these meetings. The researcher's phone number and email address will be provided for women to contact her and sign up for the study.

It is expected that fewer than 100 women will participate, and all of them will be older than 18 years of age. Participants will be compensated with \$15 for their time, and they will be given printed information about breast cancer prevention.

Describe the Informed Consent Process. Include a Copy of the Informed Consent Document:

The consent process will consist of providing each participant with a hard copy of the informed consent document, which she will be required to sign stating that she agrees to participate. The women's confidentiality will be ensured by not associating the women's names or other identifying information with the transcribed conversations. Lists including the women's contact information (used for organizing the sessions) will be destroyed by shredder or locked in a professor's office after the interviews are complete.

Women will be given the opportunity to withdraw at any time and for any reason. The women will be provided the names, email addresses and phone numbers of the researcher and her supervisor. The researcher will answer any questions the participants may have after reading the informed consent document. A copy of the interview consent form is attached.

The following contact information will be provided to all participants:

Questions/Contact Information:

If you have any questions or comments regarding the study please contact UF PhD student Heather Edwards or her supervisor, Dr. Kim Walsh-Childers. Questions or concerns regarding study participants' rights may be directed to the University of Florida Institutional Review Board (UFIRB) at **(352) 392-0433**.

APPENDIX B
INTERVIEW GUIDE

1. When I say “breast cancer,” what do you think about?
2. When I say “breast cancer prevention,” what comes to mind?
3. What kinds of things can women do, if anything, to lower their chance of having breast cancer?
4. What does breast cancer prevention mean to you personally?
 - a. Importance of mammography, BSE
 - b. Lifestyle changes?
5. What does breast cancer mean to the African-American community?
 - a. How do you, your family, and friends talk about breast cancer?
 - b. Compared to other concerns, how important do you think breast cancer is to African-American women?
6. What are some of the things you’ve heard other African-American women say about breast cancer prevention?
 - a. Why do African-American women think about breast cancer prevention the way they do?
 - b. Tell me about any programs or events about breast cancer that you’ve seen or heard about in your community.
7. Have you seen or heard information – maybe a brochure or on TV, radio, or the Internet – that tells you how to help prevent breast cancer? Tell me about what you saw or heard.
 - a. How common is it for women in your community to look for information about preventing breast cancer?
 - b. Tell me some reasons why you and your friends or family would look for information about preventing breast cancer?
8. Let’s shift subjects for a few minutes. Tell me a little about how you use the Internet.
 - a. What role does the Internet play in your life?
 - b. What role does the Internet play in your community?
 - c. Tell me about the last time you used the Internet.
 - i. What did you use the Internet for?
 - ii. How do you *usually* use the Internet?
 - d. What are some features that you like about the Internet as an information source?
 - e. What do you NOT like about using it for information?
 - f. Have any of you ever used the Internet to get health information, and if so, what for?
 - g. Tell me about a time when you looked for health information on the Internet.
 - h. What do you think about the Internet as a way to get *breast cancer* information?
 - i. How likely are women in your community to use the Internet for breast cancer information?

- j. What about you yourself? How often, if ever, have you used the Internet for breast cancer information?
- k. (For women who use the Internet for breast cancer information) I'd like to hear about your experiences looking for breast cancer on the Internet. Tell me about what you wanted to learn about breast cancer when you looked for information on the Internet.
 - i. What are some reasons why you used the Internet to find information about breast cancer?
 - ii. What sources did you use?
 - iii. How well did the information you find answer your questions about breast cancer?
 - iv. How did finding or not finding the information make you feel?
 - v. Did you use it to talk with health care providers?
 - vi. Did you make any changes in your life after learning about the prevention information?
- l. [For women who don't use the Internet for breast cancer information], what are some reasons you haven't used the Internet for breast cancer information?

APPENDIX C
SURVEY PROTOCOL SUBMITTED TO THE INSTITUTIONAL REVIEW BOARD

UFIRB 02 – Social & Behavioral Research Protocol Submission	
Title of Protocol: Survey to assess African-American women's beliefs about the Internet as a source of breast cancer prevention information	
Principal Investigator: Heather Edwards	UFID #:
Degree / Title: MAMC, MPH, PhD candidate Department: College of Journalism & Mass Communications	Mailing Address: Email Address & Telephone Number:
Supervisor: Kim Walsh-Childers	UFID#:
Degree / Title: PhD, Professor of Journalism Department: College of Journalism & Mass Communications	Mailing Address: Email Address & Telephone Number:
Date of Proposed Research: April 2009	
Source of Funding (<i>A copy of the grant proposal must be submitted with this protocol if funding is involved</i>): n/a	
Scientific Purpose of the Study: This study's purpose is to explore African-American women's beliefs and opinions about using the Internet for breast cancer prevention information. The ultimate goal of this research is to better understand how to use the Internet and other media to increase awareness of breast cancer prevention in order to reduce the mortality rates from breast cancer in African-American women.	
Describe the Research Methodology in Non-Technical Language: (<i>Explain what will be done with or to the research participant.</i>) This study will be a quantitative follow-up to the UFIRB #2008-U-887 qualitative portion of my dissertation. The survey research will incorporate the findings from prior in-depth interviews into question items on a written questionnaire. The interview guide submitted to IRB02 in the #2008-U-887 study shows the general themes explored in the total project. Participants will be asked to anonymously answer questions exploring what they think about breast cancer and breast cancer prevention as well as what they think about the Internet. The women will also provide answers to demographic questions, such as age, income, whether they have medical insurance, Internet use, education level, and other statuses that are found in the literature to relate to women's views of health and their health behavior. No details of protected health information will be collected. The women will be asked if they or their mother, sister, grandmother, or other relative has ever been diagnosed with breast cancer. Even though women with personal histories of breast cancer will not be included in the study, they will not be prevented from taking and completing a survey because some of the surveys will be administered in a group setting. Under those public circumstances, the women would effectively reveal their histories of breast cancer to the group if they did not take	

a survey. Therefore, all women within the study's age and race parameters may complete the survey, but they will mark on the questionnaire whether or not they have ever had breast cancer.

Describe Potential Benefits and Anticipated Risks: *(If risk of physical, psychological or economic harm may be involved, describe the steps taken to protect participant.)*

The potential benefit to participants is the possibility of reducing breast cancer incidence and mortality in African-American women by increasing public health researchers' and social scientists' understanding of how to best encourage cancer prevention. Also, the last page of the survey will contain phone numbers and Web addresses of organizations that provide public education about breast cancer so the participants can learn more about the disease and reducing their own risks.

Anticipated risks include potential emotional issues resulting from women with painful personal or familial experiences with cancer being asked to answer cancer-related questions. In addition to the breast cancer information resources on the final page of the survey, numbers for counseling services will be listed. Also, the women may be concerned about employers or peers learning about their family histories of cancer or their income, for example. Both of these anticipated risks will be mitigated by stressing the voluntary nature of participation. The women do not have to complete the surveys, and if they choose to do so, they can skip questions they do not wish to answer. However, the women will be encouraged to complete the survey to its fullest extent to provide the most robust information for the study, and they will be assured of their anonymity and the confidentiality of their answers. No names will be asked and no specific information that might identify a woman will be cited in the study results.

Confidentiality will be protected according to the method by which the surveys are administered. When it is possible for the surveys to be given in groups, the researcher will be present in the group to collect surveys in an envelope, and she will seal the envelope after all of the questionnaires are returned. The envelope will remain in her possession at all times while she is at the survey facility. In some cases where women fitting the study parameters may not be reached in groups, surveys may be handed out to participants by proxies, such as public librarians or church ministers. When the questionnaires are administered in this way, they will be accompanied by a pre-addressed, stamped envelope with the researcher's PO Box address on it so the participants can mail it directly to the researcher. Even though the proxies will not be responsible for collecting the surveys, the researcher will explain to them the need to ensure confidentiality and anonymity in the study.

Describe How Participant(s) Will Be Recruited, the Number and AGE of the Participants, and Proposed Compensation:

Participants will be women between the ages of 35-65 who identify as African American. A maximum of 1000 surveys will be administered. The participants will be recruited by word of mouth and in groups. For the latter, groups of women fitting the study parameters, such as churches, hobby groups, libraries, and workplaces, will be identified and the researcher will ask group attendees to complete the survey. No financial compensation will be provided to the women.

Describe the Informed Consent Process. Include a Copy of the Informed Consent Document:

The first page of the survey will describe the purpose of the study and that it is being conducted by a graduate student at the University of Florida. It will tell the potential participants that their participation is completely voluntary but that if they choose to complete the survey, the researcher will treat the surveys with strict confidentiality and will not ask for their names. Consent is implied by their reading of the consent document and then completing a questionnaire.

APPENDIX D
SURVEY INSTRUMENT

Breast Cancer Survey

Please mark the best answer or answers that describe you.

1. Have you ever looked for information about a health problem or a disease?

- Yes
- No

2. Have you ever looked for information about ways to keep yourself from getting a health problem or a disease?

- Yes
- No

3. Where do you find out about health topics? (You may choose more than one. Check all that apply to you.)

- Doctor or hospital
- TV
- Radio
- Friends or family members
- Health fairs
- Church
- Internet
- Work
- Books

4. Have you ever looked up health information on the Internet?

- Yes
- No

5. Have you ever asked someone to look up health information on the Internet for you?

- Yes
- No

6. How much time do you spend on the Internet each week?

- No time
- Less than 3 hours
- Between 3 hours and 7 hours
- More than 7 hours

7. Where do you use the Internet? (Check all of the places where you use the Internet)

- I *don't* use the Internet.
- I use it at work.
- I use it at home.
- I use it at the library.
- I use it at a friend's house, a community center, or somewhere else.

8. If you **don't** use the Internet, why **don't** you?

- I don't have time.
- I don't have access (don't have computer, cost of service).
- I don't know how to use the Internet.
- I have somebody else do it for me.
- I don't trust the information.
- The Internet is slow.
- There's too much information.

9. What do you do on the Internet? (Check all of the things you do on it)

- Play games
- Listen to music
- Read news
- Email
- Buy things
- Find maps and directions
- Look up information
- Look for jobs
- Help children with school work

10. Have you ever talked to friends and family members about breast cancer?

- Yes
- No

11. What do you think puts people at risk for breast cancer? (Check all that apply)

- A family member has or had breast cancer
- The foods they eat (diet)
- Being overweight
- Smoking
- Getting a breast hit or pulled
- Growing older
- Alcohol overuse
- Something in the environment
- Nothing. It just happens to some people.
- Other _____ (write in other risks)

12. Have you ever looked up information about breast cancer on the Internet?

- Yes
- No

13. If you looked for breast cancer information on the Internet, what made you want to find it?

(Check all that apply)

- Personal scare
- Family member or friend was diagnosed with breast cancer
- Doctor mentioned it
- Saw a pamphlet about breast cancer and wanted to learn more
- Participated in a cancer Walk or Relay event
- School project
- Just curious
- Another reason _____

14. Have you ever looked up information about *preventing* (never getting) breast cancer?

- Yes
- No

15. If you *would* use the Internet to find out about preventing breast cancer, what are the reasons you'd use it? (Check all the reasons that apply to you.)

- The Internet has a lot of information.
 - The Internet is fast.
 - The Internet makes it easy to find answers to questions.
 - The Internet lets me read about other women who had breast cancer.
 - The Internet gives me information I can share with my doctor or ask him/her about.
 - The Internet lets me talk about breast cancer with other women through email and chats.
 - The Internet has information that is easier to understand than what my doctor tells me.
 - The Internet can be used from home, at any time of the day.
 - Another reason not listed
-

16. If you *would not* use the Internet to find out about preventing breast cancer, what are the reasons you would not use it? Check all that apply.

- I don't have a computer with Internet access.
 - I don't know how to use the Internet.
 - I don't trust the information on the Internet.
 - I can't find the answers to my questions on the Internet.
 - The Internet has too much information.
 - The language on web pages is confusing.
 - Another reason not listed
-

17. If you have used any of these web sites to find health information, which ones did you use?
(Check all that apply)

- Yahoo
- Google
- WebMD
- Medline
- Mayo Clinic
- A doctor's Web site
- Other _____

18. If you wanted information about preventing breast cancer, would you want a web site that talked about breast cancer in African-American women or in women in general?

- African-American women
- Women in general
- It wouldn't matter to me.

19. What types of questions would you want answered about breast cancer? (Check all that apply)

- What causes it?
- Does it affect African-American women differently than women of other races?
- Mammography process
- How to get a mammogram if you can't afford it
- Warning signs or symptoms
- Treatments options, such as chemo and radiation
- Treatment effects
- How can I find support groups for people with cancer? How can I talk to other people with cancer?
- Diet/nutrition to reduce my risks
- Survival
- Hair falling out
- Personal stories from people who had it

Please read each sentence. Think about how much you agree or disagree with each sentence. Circle whether you *strongly disagree*, *disagree*, *agree*, or *strongly agree* with the sentence. If you don't have an opinion about the sentence, circle *No opinion*.

20. I can do something to keep from getting breast cancer.

Strongly agree Agree Disagree Strongly disagree No opinion

21. I believe I will get breast cancer during my life.

Strongly agree Agree Disagree Strongly disagree No opinion

22. I believe if breast cancer is found early, it can be treated successfully.

Strongly agree Agree Disagree Strongly disagree No opinion

23. Compared to other women my age, my chances of getting breast cancer are higher.

Strongly agree Agree Disagree Strongly disagree No opinion

24. Having a mammogram will decrease my chances of dying from breast cancer.

Strongly agree Agree Disagree Strongly disagree No opinion

25. The treatment I would get for breast cancer would be worse than the cancer itself.

Strongly agree Agree Disagree Strongly disagree No opinion

26. Being afraid of breast cancer would keep me from looking for information about preventing breast cancer.

Strongly agree Agree Disagree Strongly disagree No opinion

27. If I wanted to find out what I could do to *prevent* breast cancer, I would use the Internet to find that.

Strongly agree Agree Disagree Strongly disagree No opinion

28. I believe I could find information about breast cancer prevention on the Internet easily.

Strongly agree Agree Disagree Strongly disagree No opinion

Check one answer for each question:

29. Which describes you best?

- Single, never married
- Married
- Live with a partner
- Divorced
- Widowed

30. Do you have children?

- Yes
- No

31. Highest education finished:
- Middle school (6th-8th grade)
 - High school graduate
 - College graduate
 - Graduate school
 - Other
32. How much money do you and the people living in your house make each year combined?
- Less than \$20,000
 - Between \$20,000 and \$50,000
 - Between \$50,000 and \$75,000
 - More than \$75,000
33. Do you have medical insurance?
- Yes
 - No
34. Do you have a regular doctor that you see?
- Yes
 - No
35. Check the **3** problems that are the biggest concerns for your community.
- HIV/AIDS
 - High blood pressure
 - Diabetes
 - Heart disease
 - Abuse
 - Breast cancer
 - Sickle cell anemia
 - Other cancers besides breast cancer
 - Other problems
36. Have you ever had breast cancer?
- Yes
 - No
37. Have you ever had any kind of cancer?
- Yes
 - No
38. Have any of these people in your life ever had breast cancer?
- Yes – Mother
 - Yes – Grandmother
 - Yes – Sister
 - Yes – Aunt or cousin

- Yes – Close friend
- None of these people

39. Have you ever had a mammogram or another test for breast cancer?

- Yes
- No

40. Do you do monthly self-exams for breast cancer?

- Yes
- No

Please write your age in years (for example, 52): _____

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BIOGRAPHICAL SKETCH

Heather Edwards graduated from Samford University in 2001 with a Bachelor of Arts degree in political science and later earned a Master of Arts in Mass Communication and a Master of Public Health from the University of Florida. She began the University of Florida's doctoral program in mass communication in 2006. During the program, Ms. Edwards studied many facets of health communication and social and behavior sciences, including social marketing, doctor-patient communication, media coverage of health stories, and new media and health.

While at the University of Florida, Ms. Edwards was a graduate research assistant to Drs. Kim Walsh-Childers and Debbie Treise, and a research assistant at the Department of Veterans Affairs Rehabilitation Outcomes Research Center in Gainesville. Prior to beginning the doctoral program at the University of Florida, Edwards worked at the American Cancer Society.