KNOWLEDGE, SOURCES OF INFORMATION AND FAMILY COMMUNICATION ABOUT BREAST CANCER: A STUDY OF COLLEGE STUDENTS AND THEIR MOTHERS

by

KARYN OGATA JONES

Under the Direction of Jeffrey K. Springston

ABSTRACT

The current study seeks to investigate the perceptions and reported behaviors of male and female college students and their mothers about breast cancer under an uncertainty management (Brashers, 2001) theoretical framework. After focus groups identified key areas, a survey was designed and implemented to measure participants' knowledge about breast cancer and genetics, mass media and other sources that provide information about breast cancer, and family communication about breast cancer. Results showed participants have contradictory perceptions related to genetic risk for breast cancer: participants overestimated the number of breast cancers caused by a genetic mutation, underestimated a woman's and man's chance of passing a genetic mutation on to her/his child, and provided inaccurate risk estimates in general. Breast cancer of a celebrity, breast cancer screening recommendations, breast cancer of a person other than a celebrity, and issues related to the effectiveness of breast cancer screening were topics most frequently reported from the mass media. Breast cancer screening, breast cancer of a friend, breast cancer of a family member, and genetic factors related to breast cancer were topics most frequently reported from family communication. Other sources of information, such as physicians, campus organizations, and the Internet, were examined, as were uncertainty management strategies of participants. Suggestions for future theoretical applications include third person effect and narrative theory, and implications for research and practice are discussed.

INDEX WORDS: Breast cancer, Genetics, Uncertainty management, Mass media, Family communication, College student involvement in health issues

KNOWLEDGE, SOURCES OF INFORMATION AND FAMILY COMMUNICATION ABOUT BREAST CANCER: A STUDY OF COLLEGE STUDENTS AND THEIR MOTHERS

by

KARYN OGATA JONES

B.S., Georgia Southern University, 1992

M.A., The University of Georgia, 1994

A Dissertation Submitted to the Graduate Faculty of The University of Georgia

in Partial Fulfillment of the Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

2003

KNOWLEDGE, SOURCES OF INFORMATION AND FAMILY COMMUNICATION ABOUT BREAST CANCER: A STUDY OF COLLEGE STUDENTS AND THEIR MOTHERS

by

KARYN OGATA JONES

Major Professor: Jeffrey K. Springston

Committee: Carolina Acosta-Alzuru
Celeste M. Condit
Karen W. King
Lynne Sallot

Electronic Version Approved:

Maureen Grasso
Dean of the Graduate School
The University of Georgia
August 2003

DEDICATION

This project is dedicated to Dr. Roxanne Parrott, who is largely responsible for my journey into academia and the study of health communication.

ACKNOWLEDGEMENTS

I am grateful first and foremost to the guidance and support of my Chair, Dr. Jeff Springston, and my Doctoral Committee, Dr. Carolina Acosta-Alzuru, Dr. Celeste Condit, Dr. Karen King, and Dr. Lynne Sallot. Their suggestions and insight greatly improved the quality of the study and final document.

While so many faculty, students, and staff in the Grady College contributed to making my experiences as a doctoral student one of the most positive in my life, I would like to specifically thank some professors I had the great fortune to work with directly: Dr. Dean Krugman, Dr. Ruth Ann Lariscy, Dr. Karen Miller Russell, and Dr. Spencer Tinkham. These individuals have truly made a mark on my life.

Finally, many thanks go to my colleagues in the Communication Studies Department at Clemson University. Words cannot express how much their encouragement and support this past year has meant to me and my family.

TABLE OF CONTENTS

Page

LIST OF TABLES

Page

LIST OF FIGURES

Page

CHAPTER 1

INTRODUCTION

> I am hesitant about calling [genetic] test results 'knowledge.' To call the test results knowledge lends that information a certain status which masks the uncertainty surrounding the information, a mask which is potentially misleading to patients.
> -- doctoral student in bioethics, quoted in Green & Thomas, 1997, p. 250.

> I may have a great deal of information about a topic, I may have an amount other people would deem sufficient to make a decision ... and I even may have all the information that is currently available, yet I still may feel uncertain.
> -- Brashers, 2001, p. 478.

> Your mother, sister, aunt, daughter, niece, grandmother, best friend, you … Eight women. One in every eight women will develop breast cancer in her lifetime.
> -- message printed on educational materials distributed by a women's fraternity to college campuses nationwide.

Statement of the Problem

Between 5 and 10 % of all breast cancers are estimated to be hereditary, or caused by genetic factors (Claus, Risch & Thompson, 1991; Newman, Austin, Lee, & King, 1988). BRCA1, the first breast cancer predisposition gene, was located in chromosome 17q in 1990 (Hall, Lee, Newman, Morrow, Anderson, Huey & King, 1990). BRCA1 is "a large tumor suppression gene with 22 exons, and more than 100 mutations have been identified" (Baty, Venne, McDonald, Croyle, Halls, Nash, & Botkin, 1997). Analysis of BRCA1 mutations is possible in

"high risk families, but not yet feasible in the general population" (Baty et al., 1997, p. 223).

The recent scientific discoveries regarding possible genetic links to developing breast cancer appear to have greatly increased attention among the general public regarding learning more about the role genetics play in influencing one's risk of developing the disease. According to Andrykowski, Munn and Studts (1996), most people express interest in learning of personal genetic predisposition in cancer in general, and breast cancer in particular. Women with a strong family history of breast cancer in particular are likely to undergo genetic testing, and to be less concerned about the potential negative effects of testing than potential benefits (Clark, Bluman, Borstelmann, Regan, Winer, Rimer, & Skinner, 2000).

However, learning of one's genetic predisposition for developing a disease may also create anxiety, fear, and an increased desire to learn more about the meaning of probabilities associated with genetic risk as well as ways to manage uncertainty and risk. In attempting to learn more about genetics and breast cancer, women may seek out information from a variety of sources, and may find information that actually increases misperceptions and uncertainty. Adding to the confusion that may be caused by misinformation or conflicting information from outside sources, genetic risk, while often described in probabilistic terms (Hallowell, Statham, Murton, Green, & Richards, 1997), may be inaccurately interpreted as absolute (Hallowell, 1999; Parsons & Atkinson, 1992). Finally, deciding to undergo risk management strategies such as screening, genetic testing, and/or prophylactic mastectomy (removal of one or both breasts in the absence of disease as a preventive measure) may instead increase anxiety among women at increased risk for developing the disease (Kash, Holland, Halper, & Miller, 1992; Lerman & Schwartz, 1993; Wardle 1995), further

complicating efforts to educate and inform women about their risk and ways to manage that risk.

Goal of the Current Study

The current study seeks to provide information about the knowledge, behaviors, and beliefs among college students and their mothers regarding genetics and breast cancer, media and organizational messages about breast cancer, and family communication about breast cancer.

Justification

While a primary focus of the current study is on participants' perceptions related to genetic risk for breast cancer, this is only one area where more research is needed in helping individuals understand breast cancer. In addition to those women who have a known increased risk for developing breast cancer due to heredity, many others are likely to be concerned about issue such as screening guidelines, diagnosis and treatment options, and helping friends and family members diagnosed with breast cancer cope with the disease.

More research is needed to document the importance of family communication on talk about breast cancer issues in general, with specific attention to including the perceptions of male family members and their participation in family talk about breast cancer; the types of information women and men hear and read about breast cancer in the mass media and their interpretations of such information; and the perceptions of college-aged men and women specifically with regard to breast cancer issues. The latter is particularly needed given recent efforts by agencies such as the Susan G. Komen Breast Cancer Foundation and American Cancer Society to involve college students in education and fundraising activities. Research should be conducted which illustrates the potential effects of such efforts to assist health communication scholars and practitioners in developing appropriate messages and campaigns. In

short, the current study seeks to provide more information in these areas through systematic, quantitative study of a convenience sample of college women and men and their mothers.

CHAPTER 2

RATIONALE

(Mis)Perceptions Related to Genetic Risk and Breast Cancer

Research has shown that women tend to overestimate the impact of genetics on the development of breast cancer among the general population and have inaccurate perceptions about their own personal risk (Hallowell, Green, Murton, & Statham, 1995; Hallowell, Statham & Murton, 1998; Henderson & Kutzinger, 1999; Karp, Brown, Sullivan, & Massie, 1999; Sagi, Kaduri, Zlotogora, & Peretz, 1998; Wonderlick & Fine, 1997). These perceptions can remain even after a woman receives education from a genetic counselor (Evans, Blair, Greenhalgh, Hopwood & Howell, 1994; Hallowell, 1999; Hallowell & Murton, 1998; Lerman, Lustbader, Rimer, Daly, Miller, Sands & Balshelm, 1995; Lloyd, Watson, Waites, Meyer, Eeles, Ebbs, & Tylee, 1996; Sagi, Kaduri, Zlotogora, & Peretz, 1998).

Breast cancer genetics is a complex topic, and identifying a person's risk is based on calculating probabilities, which can be difficult to understand and apply to decisionmaking about ways to manage risk. Individuals understand and perceive presentations of risk information differently (Hallowell, Statham & Murton, 1998; Richards et al., 1995), so some strategies (i.e. quantitative/numeric or qualitative) will be more or less preferred depending on the individual, and thus have varying impact in counseling and educational efforts (Green, Richards, Murton, Statham & Hallowell, 1997; Hallowell & Murton, 1998; Hallowell, Statham & Murton, 1998; Hallowell, Statham, Murton, Green & Richards, 1997). Finally, Woloshin, Schwartz, Moncur, Gabriel and Tosteson (2001) point out that those without strong quantitative skills, called "numeracy," will have difficulty understanding and interpreting numbers. These authors

conclude that limited numeracy may be an important barrier to overcome in conducting patient assessments and providing information. Indeed, given the nature of the science of genetics, attempts to educate individuals regarding genetic risk and breast cancer may only serve to create confusion among those attempting to gain a better understanding of the role of genetics in the disease.

The Mass Media and Breast Cancer

It appears that one of the most influential external sources of information about genetics and breast cancer is thought to be the mass media in general. Mass media sources, including television and newspapers, are identified by several researchers as having a direct influence on women's perceptions, knowledge, and attitudes about breast cancer and the impact of genetics on the disease (i.e., Hallowell, Statham & Murton, 1998; Henderson & Kitzinger, 1999; Richards et al., 1995; Wonderlick & Fine, 1997). For example, studies have pointed to the mass media's overemphasis on the impact of genetics on breast cancer (Sagi, Kaduri, Zlotogora & Peretz, 1998) and inaccurate or misleading reports about outcomes of genetic testing (Richards, Hallowell, Green, Murton & Statham, 1995; Wonderlick & Fine, 1997) as contributing to women's over-estimations of not only the impact of genetics on the development of breast cancer among the general public, but also their own personal risk for developing the disease.

Conversely, due to the perceived emphasis on genetics and breast cancer, a lack of perception of personal risk may result from the absence of genetic predisposition. Since about 5 to 10 % of breast cancers are estimated to be hereditary, the large majority of women who develop breast cancer will not have an observed genetic predisposition, and may mistakenly conclude based on the recent focus on the impact of genetics on breast cancer that they are not susceptible to developing the disease. This misperception could in turn contribute

to a later diagnosis, lowering chances for less intensive treatments, and ultimately, survival.

For example, Sutton, Balch and Lefebure (1995) offer a criticism of public health messages' reliance "solely on clinical and epidemiologic research as the basis for messages," a strategy that, they argue, "leads to messages that present 'the facts' about a specific health behavior, on the assumption that exposure to these facts will lead to the desired behavior" (p. 725). To illustrate this criticism, they offer an assessment of perceptions related to recently published information about genetic risk for breast cancer as an example of how this common health communication approach can backfire:

> A message widely disseminated to women was that women with a family history of breast cancer were at greater risk of having breast cancer themselves. The intent was to increase women's knowledge about risk factors for breast cancer so that they would seek appropriate screening. However, subsequent consumer research has found that this health message, once processed through the consumer's reality, was translated as 'If I don't have breast cancer in my family, I don't need to worry about breast cancer.' Lack of family history of breast cancer is now a primary reason women give for not having a screening mammogram. (Sutton et al., 1995, p. 725.)

Based on the above observations, the current research will investigate the following prediction:

> H1: Most mothers and students will overestimate the role of genetics in the development of breast cancer.

This prediction, while apparently supported in previous research, is important to verify in the present study as a founding basis for the remaining research questions. In addition, none of the studies reviewed here specifically indicate that they included college students as study participants, so designing a study for this group in particular could yield new, useful information regarding younger men and women's perceptions about the relationship between family history and the risk for developing breast cancer.

As stated above, several researchers assert that media coverage has affected women's perceptions about genetics and breast cancer. A handful of studies have specifically attempted to analyze or interpret the actual content of mass media representations of breast cancer and the possible effects of these representations on women's behaviors, knowledge, and beliefs. For example, Condit (1999) found that the majority of randomly selected mass media magazines in the United States from 1980 to 1995 included in her study featured "dominantly positive" content about genetics.

In another study, after conducting an analysis of media reports about breast self-examination (BSE), Kline (1999) argues that the popular media articles reviewed, while widely recommending the practice, "provide little if any substantive rationale that there is any benefit to BSE."[1] She further concludes that the mass media messages about BSE, when taken together, consist of an "agency-robbing discourse" that "blames women for not doing their part to reduce high breast cancer mortality statistics, establishes the locus of all reasons for refraining from the activity with the woman, and chastises these women for failing to engage in the activity" (p. 119). Clearly, such discourse could have an

[1] It appears that Kline may have been ahead of her time in pointing out the lack of evidence supporting the benefits of conducting BSE. A recently published clinical study (Thomas et al., 2002) comparing women participating in intensive BSE training with a control group found intensive instruction in BSE did not reduce mortality from breast cancer and instead increased the chances of benign (non-cancerous) breast biopsies.

impact on women's perceptions about breast cancer, and potentially add to the uncertainty women experience related to breast cancer screening, diagnosis, and treatment issues.

In other research, Sheedy (2000) uses Burke's comic frame to analyze breast cancer genetics discourse in newspapers over a decade. To summarize, Sheedy found a marked shift in dominant themes present in the discourse: from an almost Utopian vision of the impact of genetic research on breast cancer morbidity and mortality in the initial phase of reporting; to a more cautious, "embodied scene" in the middle stage, when the imagined possibilities of earlier discourse became considered in various social, ethical, moral, and legal contexts; to the final phase, when discourse began to focus on debates about the commercialization of genetic testing for breast cancer. She found the overall attitudes expressed about breast cancer genetics began as "supportive," shifting to "mostly supportive with some concern," to "equal support and concern" as the discussions matured over time. She identified the primary "acts" as discoveries about breast cancer genetics and the primary "actors" as researchers and women in "high risk" families, with others such as breast cancer activists and psychologists entering the discussion in later media representations.

In contrast to the above analyses based on public discourse on genetics, two studies attempted to specifically tie media content about breast cancer to women's perceptions, knowledge, and behaviors. One study attempted to directly examine the effect of a specific media event on women's knowledge and behaviors about breast cancer. As part of a community-based study, Lane, Polednak and Burg (1989) made both within-subject (cohort) and independent sample comparisons before and after media announcements that Nancy Reagan, wife of then-President of the United States, Ronald Reagan, had been diagnosed with breast cancer, "detected at an early stage by mammography" (p. 1551).

The survey included questions about past behavior (mammography, "breast physicals," and self-examination), concerns about mammography, knowledge of breast cancer risk, and demographics.

Based on these surveys, Lane et al. (1989) found "the slight increase [observed] in knowledge of risk was not accompanied by an increased sense of personal susceptibility to breast cancer" (Lane et al., 1989, p. 1552). Furthermore, while almost all women over the age of 50 reported hearing about Reagan's experience with breast cancer through the media, only a slight increase in knowledge of risk was observed, and no significant increases in participants' sense of personal susceptibility to breast cancer were observed. A small percentage of participants in the survey reported being directly influenced to contact a health professional (6-8 %) and to have their first mammogram (1.5-2 %) as a response to reading about Reagan's experience with breast cancer. Therefore, the authors of this study express uncertainty regarding whether or not mass media "awareness" activities themselves have an impact on women's knowledge, perceptions, and behaviors related to early detection of breast cancer.

In a more recent study, Henderson and Kitzinger (1999) conducted a content analysis of media reporting on inherited breast cancer and focus group discussions with "ordinary women" about breast cancer to determine the influence of media representations on women's knowledge and perceptions. The researchers found that most of the reporting fell into four categories: "scientific discoveries," "debates about testing," "controversies over patenting," and "human interest stories," with "the single most dominant strand of reporting about inherited/genetic risk during 1995-1997 focus[ing] on issues surrounding prophylactic mastectomies and the experiences of women from 'high risk families'" (p. 565).

In addition to their content analysis of media messages, Henderson and Kitzinger (1999) conducted focus groups to attempt to identify the impact of media stories on "ordinary women." The researchers found that most participants in these discussions greatly overestimated the role of genetics in the etiology of breast cancer: most participants stated a figure of over 50 % when asked to estimate the proportion of women who had developed breast cancer because of a family history of the disease. Furthermore, "the importance of family history was also evident in the way that women discussed their own risk," since "women with just one relative, or a couple of elderly relatives who had breast cancer sometimes gave this as a reason for feeling at risk" (p. 572). Henderson and Kitzinger (1999) conclude, "the emphasis placed on inherited risk cannot, of course, be entirely attributed to specific media coverage, ... [but] the key role of the media in informing women's assessments was clearly evident in the way in which women referred to the media to explain and justify their emphasis on family history" (p. 572).

Condit (2001) specifically calls for research that includes an assessment of mass media messages about genetics. In a discussion of public opinion and genetics, she writes, "regardless of the distortions that exist, ... the mass media provides the main venue for 'public talk' in most Western industrialized nations at present ... Although the discourse that we hear and see in the mass media should not be taken as an accurate reflection of what lay people are thinking, this discourse does constitute an important part of the commonly available depictions of key social issues" (pp. 813-814). Television in particular is believed by communication scholars to be highly influential among Americans in general: as Gerbner, Gross, Morgan, Signiorelli, and Shanahan (2002) write, "transcending historic barriers of literacy and mobility, television has become the

primary common source of socialization and everyday information … of otherwise heterogeneous populations" (p. 44).

Given the limited amount and somewhat inconclusive nature of research that directly assesses the content of media representations of breast cancer, including discussions about the relationship between genetics and breast cancer, more should be done in this area to identify specific sources of information about genetics and breast cancer and the perceived accuracy of these information sources. Thus, the initial research questions in this study ask:

RQ1a: What kinds of information do mothers and students read about breast cancer, including the impact of genetics on breast cancer, in newspapers and magazines?

RQ1b: What kinds of information do mothers and students obtain about breast cancer, including the impact of genetics on breast cancer, from television?

RQ1c: What are the assessments and interpretations mothers and students make about the information about breast cancer they obtain from newspapers, magazines, and television?

Family Communication and Breast Cancer

Family communication is, understandably, a central issue in genetic counseling research. Indeed, according to Green, Richards, Murton, Statham and Hallowell (1997), "genetic counseling is a family affair" (p. 56). Genetic counseling for breast cancer is unique because women who come for genetic counseling already perceive themselves to be at high risk based on family history of the disease. Because of this unique situation, these women may be looking not so much for a specific risk estimate, but instead for ways to manage and

cope with their perceived elevated personal risk (Hallowell et al., 1997; Richards et al., 1995). Women who are in "high risk" families are likely to have a great deal of anxiety about developing breast cancer, having watched close family members undergo treatment and sometimes die (Gagnon, Massie, Kash, Gronert, Heerdt, Brown, Sullivan, & Borgen, 1996; Kash, Holland, Halper, & Miller, 1992; Lerman, Trock, Rimer, Jepson, Brody, & Boyce, 1991). The anxiety these women experience is likely to influence their perceptions about their own risk for developing breast cancer and their decisions about risk management strategies. The finding that many women whose mothers or sisters have had breast cancer tend to estimate the age they themselves are most likely to develop breast cancer as the same ages their relatives developed the disease (Richards et al., 1995) clearly illustrates the impact of family experiences on perceptions of personal risk.

Family communication is also a central issue in genetic risk for breast cancer because detailed knowledge about family history of cancer is crucial in making accurate interpretations related to one's risk for developing breast cancer. According to Green and Thomas (1997), "in the absence of a thorough family history, the presence of a BRCA1 mutation and breast cancer in the mother alone do not provide the basis for assuming the existence of 'hereditary' breast cancer in the family" (p. 250). Furthermore, if a genetic mutation is identified that signals an increased risk for developing the disease, other family members will also be at higher risk and may or may not choose to be informed about their personal risk (Green et al., 1997; Green & Thomas, 1997; Hallowell & Murton, 1998; Richards et al., 1995).

Family members are often critical support networks, particularly when one is undergoing a serious illness such as breast cancer. The influence of family members as sources of support when making decisions regarding risk

management strategies such as undergoing genetic testing (Clark et al., 2000), screening, and prophylactic mastectomy (Hallowell, 1999; Karp et al., 1999; Richards et al., 1995) has specifically been noted. In addition, one study found that female relatives, particularly mothers, were the most likely family members with whom women shared information, questions, and concerns about breast cancer (Green et al., 1997). Therefore, female family members in particular may be an important source of information about breast cancer.

College Campuses as Sources of Information About Breast Cancer

Another potentially important source of information, at least for younger men and women, stems from the activism that occurs in support of breast cancer on college campuses and surrounding communities. For example, the women's fraternity, Zeta Tau Alpha, adopted the Susan G. Komen Breast Cancer Foundation as its national philanthropy in 1992 (Hansen, 2002). Educational materials distributed to college women by the fraternity (Appendix A) reveal the organization's rationale for its involvement in breast cancer education and awareness activities: "because ZTA is a woman's organization, we realize the importance of breast cancer education and awareness."

The fraternity currently has active chapters at approximately 222 colleges or universities; according to a fraternity spokesperson, all active chapters are required to participate in sponsoring efforts to raise money and awareness for the Komen Foundation. In addition to raising money for the Komen Foundation, as part of its "Don't be a fool … Do monthly breast self-examinations" campaign, the fraternity distributes educational shower cards, depicting instructions for monthly breast self-examination and screening recommendations, to women's dormitories and sorority houses (see Appendix A). According to the Komen Foundation, shower card distribution by these college women is in the millions and counting. In addition to the shower cards, the fraternity also distributes

breast self-examination stickers (designed to be placed on women's calendars as reminders to conduct monthly self exams) to other female students. While the fraternity has not conducted a formal evaluation of the distribution of these materials, according to a fraternity spokesperson, all chapters participate in these awareness activities to some extent. The fraternity's chapters also frequently sponsor on-campus educational sessions on breast cancer for various women's organizations, and they provide volunteers and publicity each year for the Komen Foundation's "Race for the Cure," events which raise money for breast cancer research and education nationwide. These events are scheduled to take place in about 2,800 college campuses or nearby communities in 2003.

Another breast cancer education and fundraising event popular with college students is the American Cancer Society's "Relay for Life." According to the American Cancer Society, Relay for Life is the organization's "signature activity." Relay "teams" camp overnight at schools, parks, and fairgrounds and take turns walking or running around a track or path. Each team is asked to have a representative on the track at all times during the overnight (typically 24 hours) event. The purpose of the Relay is "to support the American Cancer Society's mission" and raise funds through donations secured by each team (www.cancer.org). Teams are formed from businesses, schools, clubs, families, friends, hospitals, churches, schools, and service organizations.

According to an American Cancer Society/Relay for Life representative, targeting colleges with awareness and education activities such as Relay for Life is a new, highly successful phenomenon. College communities are "captive, willing, able audiences," and campus organizations (such as sororities and fraternities) conduct regular meetings that allow for contact and event communication. Students are perceived to have the available time and money to participate, can get their friends involved, and have few external obligations that

would interfere with participation. According to this representative, students and faculty at the university from which participants in the current study were recruited have participated in Relay for Life for six years, and raised about $100,000 in their first Relay. This representative predicts that the University will probably raise $150,000 for the American Cancer Society in this year's event.

Given these and other efforts apparently designed to increase college students' awareness of issues surrounding breast cancer, college students themselves are a group who could potentially shed light on the impact of these efforts. Additionally, since the genetic counseling literature specifically points to the importance of family communication in issues related to breast cancer, research should be done to evaluate the extent to which students and their families discuss breast cancer. More specifically, research should be done to assess whether or not college students are sharing the information they receive from campus organizations and other sources about breast cancer with their mothers or other female relatives, since these relatives are likely to be within the age group when annual mammography and clinical breast examinations are generally recommended. For these reasons, the current research is specifically designed to include college students and their mothers. To examine the potential communication that may exist among college students and their mothers about breast cancer, the next set of research questions asks:

RQ2a: How often do female college students and their mothers discuss breast cancer?

RQ2b: How often do male college students and their mothers discuss breast cancer?

RQ2c: If college students discuss breast cancer with their mothers, what specific topics do they discuss?

RQ3: What relationships, if any, exist among students' and their mothers' perceptions about breast cancer and reported family communication about breast cancer?

Other Sources of Information

Besides family members and the media, other sources of information about breast cancer may have an influence on college students and their mothers. For example, Wonderlick and Fine (1997) found that doctors and books were identified as two of the three most important sources of information about genetics and breast cancer among study participants, in addition to newspapers. In comparison, Clark, Bluman, Borstelmann, Regan, Winer, Rimer and Skinner (2000) found that while "talking with physicians" was identified as a top coping strategy, physicians were less of an influence than spouses, sisters, children, and parents when making testing decisions.

Genetic counselors are clearly an important source of information, even though their efforts appear to have varying effects on women's perceptions and decisions about determining genetic risk (Clark et al., 2000; Green et al., 1997; Hallowell et al., 1997; Hallowell, Statham & Murton, 1998; Richards et al., 1995; Sagi, Kaduri, Zlotogora & Peretz, 1998). Such interpersonal sources of information should be studied further to learn more about their potential influence related to informing others about breast cancer, and how the information provided by these sources is used in conjunction with the information provided by the mass media and family members.

In addition to interpersonal sources of information that may be important to women in learning more about genetics and breast cancer, Cartwright (1998) proposes that "alternative" texts such as artistic representations of breast cancer have the potential to form "communities and public cultures on the basis of

breast cancer politics" and re-evaluate our meanings of beauty, age, race and cultural identity (p. 123). Cartwright cites sculpture and photography as specific examples of these representations. She writes that this new concept of community reflects "a blurring of boundaries between institutional health cultures and countercultures, and between mainstream and alternative media venues and audiences" (p. 136). Finally, organizational texts such as the educational efforts of campus and community organizations mentioned above could be considered an important source of information within these communities.

To attempt to gather information about these additional potential sources of information about breast cancer among college students and their mothers, the next set of questions for this study asks,

RQ4a: Who/what are other potentially important sources of information about breast cancer besides family and the mass media?

RQ4b: What kinds of information do mothers and students get from these other sources?

RQ4c: What are the assessments and interpretations mothers and students make about the breast cancer information they obtain from these other sources?

Managing Uncertainty and Breast Cancer

In an outline and extension of uncertainty management theory as applied to health communication practice, Brashers (2001) defines uncertainty and provides a discussion of its role in everyday life. He writes, "uncertainty exists when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in

general" (p. 478; see also Babrow, Hines, & Kasch, 2000; Babrow, Kasch & Ford, 1998). Uncertainty can serve a variety of functions. For example, "in some instances, people may want to reduce uncertainty because they find it threatening. At other times, uncertainty allows people to maintain hope and optimism. Across contexts, people engage in or avoid communication so they can manipulate uncertainty to suit their needs" (Brashers, 2001, p. 491). Therefore, uncertainty can be positive or negative, depending on its function at a particular time and in relation to a particular situation.

Uncertainty is a predominant theme in academic discussions about breast cancer and genetics. Its presence is evident in studies about genetic counseling sessions (Hallowell et al., 1997; Hallowell & Murton, 1998; Richards et al., 1995; Wonderlick & Fine, 1997); the processes women undergo when making decisions related to managing their risk for developing breast cancer (Green et al., 1997; Green & Thomas, 1997; Hallowell, 1999; Karp et al., 1999; Kline, 1999; Richards et al., 1995); women's interpretation of personal and population-based risk estimates (Hallowell, Statham, & Murton, 1998; Henderson & Kitzinger, 1999); and the descriptions of the influence of media reports about genetics and breast cancer (Richards et al., 1995; Sagi et al., 1998; Wonderlick & Fine, 1997).

Uncertainty and Education on Genetic Risk for Breast Cancer

Health in general is one area Brashers (2001) specifically notes as a context that is "unpredictable, complex, and ambiguous" (p. 480) -- thus an area likely to involve a high degree of uncertainty, and a desire to manage uncertainty, among participants. For example, medical decision-making in general is "a context in which uncertainty is typical. Health care providers and patients both encounter complexity and ambiguity in decisions about diagnoses and treatment options ... Treatment options vary and their corresponding

efficacy may be debated (e.g., controversy over the use of various treatments for breast cancer)" (Brashers, 2001, p. 479).

As indicated earlier, the genetic counseling setting is one health setting within the medical decision-making context where both providers (counselors) and their clients are likely to experience uncertainty, even after counseling is completed. Unfortunately, to complicate matters, the counseling session itself may create more uncertainty than it resolves, since counselors may vary in their presentation of risk information to clients and often rely on providing risk estimates in terms of probabilities when attempting to explain genetic risk to clients (Hallowell, et al., 1997; Hallowell, Statham & Murton, 1998).

Furthermore, while women have expressed an interest in reducing perceived risk of developing breast cancer and in receiving assistance in deciding with whom and how to discuss their genetic risk for developing breast cancer, they also express difficulty in understanding risk estimates (Richards et al., 1995). Given the uncertainty that occurs in these sessions, it seems reasonable to consider the possibility that women and their families among the general population may be uncertain about the role of genetics in developing breast cancer, and exposure to information about breast cancer through the mass media or other sources may or may not help to manage that uncertainty.

Indeed, Brashers (2001) writes, "I may have a great deal of information about a topic, I may have an amount other people would deem sufficient to make a decision ... and I even may have all the information that is currently available, yet I still may feel uncertain" (p. 478). This sentiment is clearly reflected in statements made by participants in one study regarding women's decision-making about prophylactic mastectomy (removal of both breasts as a preventive strategy):

> They [participants] all expressed a wish for more definite data than the risk assessments available. Although one group member's family had participated in research genetic testing for BRCA1, the results, disappointingly, had been inconclusive. Another group member had organized relatives to donate blood samples for BRCA1 mutation testing. Despite their many valiant attempts to gather scientific facts, the women expressed a continual sense of frustration at the lack of 'hard data' on which to base their decisions about [prophylactic mastectomy]. (Karp, Brown, Sullivan, & Massie, 1999, p. 167)

Green and Thomas (1997) specifically address issues of "informational uncertainty" that arise when attempting to assist clients in making decisions based on genetic risk estimates. They quote a doctoral student in bioethics who participated in a case discussion about familial conflict over genetic testing for breast cancer: "I am hesitant about calling [genetic] test results 'knowledge.' To call the test results knowledge lends that information a certain status which masks the uncertainty surrounding the information, a mask which is potentially misleading to patients" (p. 250). Another participant in this discussion commented, "One must keep in mind that other genes as well as other multifactorial etiologies not yet identified may cause increased risk of breast cancer. Likewise, I would add that a false or uncertain positive can also do harm, for example, by leading to an unnecessary surgical procedure" (Green & Thomas, 1997, p. 250).

A final area of informational uncertainty related to breast cancer, and one specifically articulated in this research, is "the degree of breast cancer risk reduction afforded by preventive interventions, ... [since] the literature in this area remains inconclusive on the most effective intervention strategies" (Green & Thomas, 1997, p. 251). In other words, not having a specific recommendation

for diagnosis and treatment strategies in a given situation may prevent health practitioners from effectively reducing or managing uncertainty, both within themselves and their patients.

This uncertainty is in turn echoed by the news media in their attempts to report medical information about breast cancer screening. As Kahl and Lawrence-Bauer (1996) observe,

> Regardless of the media used to disseminate news concerning mammographic screening, the messages are rarely strong and clear, even when fear appeals are employed to generate response. News stories, in particular, garble the messages of public health campaigns and generally discourage mammographic testing by focusing on questionable issues still being debated rather than facts that have been established. News stories too often leave the impression that women are somehow at fault for the increased incidence of breast cancer. (p. 312)

The authors continue, citing specific examples of confusing media messages in such popular media as the New York Times newspaper and Time and Self magazines. These observations underscore the need to address issues of informational uncertainty related to interpersonal and mediated messages about breast cancer.

Uncertainty Management Strategies Related to Genetic Risk for Breast Cancer

According to Brashers (2001), engaging in uncertainty management can take the form of the following activities: "seeking and avoiding information"; "adapting to chronic uncertainty," where accepting uncertainty is an adaptive mechanism; "social support as assisted uncertainty management," where "supportive others facilitate uncertainty management with messages and behaviors that increase and decrease certainty and uncertainty;" and managing

uncertainty management, or "the need to balance uncertainty management with other tasks" that "often results in competing goals" (pp. 482-486).

Clearly, women have been found to use many of these strategies when faced with decisionmaking about risk management options. These options seem to include (a) screening; (b) genetic testing; (c) prophylactic mastectomy; (d) undergoing genetic counseling; (e) relaxation techniques; (f), changing eating habits and exercise behaviors; and (g) information-seeking, including reading books and newspapers and talking with friends, relatives, and doctors (Clark et al., 2000; Hallowell, 1999; Richards et al., 1995). Therefore, the perceptions and experiences to be studied in the current research, namely, discussing breast cancer with family and others and providing assessments related to information gained from mass media reports and other sources about breast cancer, can affect one's uncertainty, and in turn influence uncertainty management strategies. Indeed, activities such as discussing breast cancer with family members and participating in activist events such as fundraising walks may even represent uncertainty management strategies themselves to participants.

The 'Culture of Chronic Illness' and its Relationship to Uncertainty Management Strategies Used to Understand or Reduce Breast Cancer Risk

Medical research developments in recent years, including breakthroughs in cancer detection, treatment, and the identification of genetic factors that influence one's risk of developing the disease, have likely benefited thousands of people. However, these developments may have a downside: a phenomenon Brashers (2001) calls "the culture of chronic illness." Brasher's concept is similar to language used in medical circles, when health professionals describe healthy clients who are overly concerned about their health as the "worried well." This culture, Brashers argues, is a result of "the communication of health risk information for disease prevention and control [that] has increased rapidly over

the past two decades," combined with the epidemiological information about risk that can now "be derived from behavioral factors such as eating unhealthy foods, smoking or chewing tobacco products, drinking alcohol, or taking drugs, and from markers such as familial history or genetic predispositions to diseases such as cancer and heart disease" (p. 406).

This new information has resulted in a slew of recommended behaviors for individuals, designed to help decrease morbidity and mortality rates. For example, "people are encouraged to perform self-exams on their breasts or testicles, get regular mammograms or prostate screening, and check their cholesterol levels and blood pressure" (Brashers, 2001, p. 406). In short, surveillance medicine seems to paint a picture of people or populations hanging "precariously between health and illness" (Armstrong, 1995, p. 396).

Brashers (2001) provides a dramatic example of this culture:

> The Chicago Tribune recently reported the story of a woman whose genetic testing indicated high likelihood of breast and ovarian cancers. After undergoing a prophylactic oophorectomy (removal of the ovaries) and agreeing to frequent monitoring of her breasts to avoid a prophylactic mastectomy (removal of the breasts), an error in her test results was discovered. She had been given the results of another woman, and her own tests turned out to be unremarkable. (p. 487)

The above anecdote specifically illustrates the concerns voiced by participants in Green and Thomas's 1997 study presented earlier. Brashers notes that this woman's story is important for two reasons. First, "genetic testing intended to reduce uncertainty about cancer potential created such anxiety in the woman that she was willing to undergo radical surgery in the absence of any sign of cancer. Rather than opting to closely monitor her health, she chose to eliminate the ongoing uncertainty that would accompany that choice" (2001, p.

488). Second, "the tragic circumstance of the switched test result, and the very public display of that error, will lead to new uncertainties about the accuracy and reliability of testing procedures for herself and others" (2001, p. 488). In conclusion, "although the benefits of testing are sometimes great (e.g., finding a malignancy early so it can be treated successfully), the psychological costs of surveillance must also be weighed ... People may be so disturbed by information they avoid it at all costs" (Brashers, 2001, p. 488). Thus, uncertainty may be preferred to securing information about one's personal risk estimates, given the potential consequences of learning of one's predisposition for developing a disease.

Based on propositions of uncertainty management, the current research proposes an overall and final question, taking into account the variety of literature on the influence of the media and other sources on women's perceptions about breast cancer and genetics and ways individuals are likely to attempt to manage uncertainty related to breast cancer and genetics:

> RQ5: What uncertainty management strategies (such as recommending or participating in screening, participation in genetic counseling and/or genetic testing, communicating with others about breast cancer, and high levels of media exposure) are reported by mothers and students?

CHAPTER 3

METHOD

To investigate the above prediction and questions, a survey of college students and their mothers was designed. While breast cancer is largely seen as a woman's issue, the current study included male students and their mothers in an attempt to capture new information about knowledge, sources of information, and the importance of family communication and breast cancer. The survey (Appendix C) consists mainly of a series of closed-ended questions designed to explore the hypothesis and research questions, with some additional open-ended items designed to capture any relevant information not obtained in the close-ended items.

The development of the survey was assisted by reviewing existing quantitative studies in breast cancer and genetics, conducting four exploratory focus groups, and conducting a pilot study of the survey. The focus groups, conducted with male students (one group), female students (two groups), and mothers (one group), were designed to assist the researcher in the development of specific questions and topics to include in the survey relative to the hypothesis and research questions (see Appendix B for moderator guide and transcripts). Participants for the student focus groups were recruited from an upper-level public relations administration course at a large southeastern land grant university. Participants for the mothers focus groups were recruited from the same university's administrative/support staff. All focus groups were conducted in the Fall of 2002. Three male students, 14 female students, and three mothers participated in the focus groups. The student participants received course credit for their participation; the mothers received lunch for their participation.

After the focus groups were conducted and reviewed, the survey was developed, and a pilot of the survey was conducted to help identify potential problems or confusing items. The pilot was conducted in a mid-size university located about 100 miles from the university where the participants for the main study were recruited. Twenty-six students (20 female and six male) completed the pilot survey and gave written and oral feedback to the researcher regarding items and/or instructions they found to be problematic. These students also offered suggestions related to the organizational format and overall appearance of the survey.

After editing the survey based on the pilot, the final quantitative survey was completed and administered in late fall semester, 2002. The student participants were recruited from an introductory-level public relations course at a large southeastern university. Students received course credit for their participation, but only if surveys were received from both the students and their mothers. This decision was specifically recommended by focus group participants as a method for increasing the number of mothers who would complete and return the survey. If the mother of a student was not available, the student was instructed to recruit a close female family member, such as an aunt, to participate. Participants were informed of the expectations of the study, that no stresses or risks were foreseen from their participation, and that they could stop participating at any time without penalty. Informed consent was then obtained from the participants in writing.

Data were collected initially from the students. Students completed the surveys in a supervised setting immediately following a class lecture or individually if they were not present at the time the survey was administered to the entire group. Students were then instructed to have their mothers complete the surveys during a break in the semester and bring the completed surveys

back with them upon returning from the break. One student's mother's survey was mailed to her after the student indicated to the researcher that she would not be seeing her over the break; the rest of the students indicated that they would be able to deliver the surveys to their mothers/female relatives and return them. Students returned their mothers' surveys in signed, sealed envelopes to the researcher upon returning from the break. Students who completed surveys during the supervised class meeting spent approximately 10 minutes on average completing the survey; it is not known how long the mothers spent completing the survey since their participation was not directly supervised due to time and distance constraints. All participants were provided with the researcher's telephone number and e-mail address and directed to contact her if they had any questions or concerns. In the researcher's absence, the course teaching assistant was trained on administering and collecting the remaining students' and mothers' surveys, and was also instructed to contact the researcher to resolve any questions or problems about the survey.

To investigate the hypothesis that most participants would overestimate the impact of genetics on the development of breast cancer, participants were asked to respond to the following four items (from Wonderlick & Fine, 1997): "In your opinion, what is the chance for any woman to develop breast cancer during her lifetime," "in your opinion, what percentage of all breast cancer cases are caused by a gene mutation," "if a woman carries a gene mutation associated with breast cancer, what do you think is the chance that she will pass the gene on to any child she has," and "if a man carries a gene mutation associated with breast cancer, what do you think is the chance that he will pass the gene on to any child he has?" For the final two questions, respondents were asked to provide their best guess if they were not sure.

To investigate the first set of research questions related to breast cancer information in newspapers and magazines, participants were asked how frequently they read about breast cancer in magazines and newspapers and heard about breast cancer on television, the specific kinds of information they hear and from which specific sources, and how accurate they perceive this information to be. Checklists for the sources of information and topics were generated from a review of the literature as well as topics and sources that emerged from the focus groups. For both the print (newspaper and magazine) and television items, the following topics were provided: "breast cancer of a celebrity," "breast cancer of a person other than a celebrity," breast cancer screening recommendations," "issues regarding the effectiveness of breast cancer screening practices," "stories about women who had a gene that predisposed them to breast cancer," "statistics about how often genes cause breast cancer," "stories about how genes play a role in breast cancer," and "environmental factors related to breast cancer," as well as an "other" fill-in option.

For the specific sources of print (newspaper and magazine) information, the local major city newspaper was provided as an option, as well as "other major city newspaper," "national newspaper," "other hometown/local newspaper," the university's student newspaper, "organizational magazine," "women's magazine," "news magazine," an "other" fill-in option, and "don't know/can't remember" were all provided as possible choices. For the specific sources for television, "local news," "national news," "local programming other than news," "national programming other than news," "public broadcasting program or news," "cable/satellite channel program," an "other" fill-in option, and "don't know/can't remember" were provided as options. Participants were instructed to check all that apply in these items. To assess participants'

interpretations of these sources of information about breast cancer, participants were then asked how confident they are that the information from newspapers, magazines, and television is accurate, on a 5-point scale from "not at all confident" to "extremely confident."

To investigate the second set of research questions related to family communication about breast cancer, participants were asked how often, on average, they discuss breast cancer with the family member participating in the study with them, on a six-point scale from "never" to "every day." Participants were then asked what specific breast cancer topics they discuss with family members. Options here included "breast cancer of a family member," "breast cancer of a friend," "breast cancer of a celebrity," "breast cancer screening," "genetic factors related to breast cancer," "environmental factors related to breast cancer," and an "other" fill-in option. Participants were also asked how often they have recommended to the female family member participating in the study with them that she do self breast examination, have a mammogram, and have a clinical breast examination. The options for these items were based in part on current screening recommendations and adapted from existing literature, and ranged from "never" to "daily."

To further identify communication between mothers and college students specifically related to breast cancer, student participants were asked how frequently, if ever, they have given information about breast cancer to their mothers, and if so, what kinds and from which sources. Mothers were asked how frequently their students gave information about breast cancer to them, and if so, what kinds and from which sources. For these questions, mothers and students were presented with the same category and source checklists. Categories included information about screening, including how to obtain a mammogram and screening guidelines (three categories); genetics information,

such as statistics about how often genes play a role in the development of breast cancer (three categories); information on fundraising events such as walks and races (one category), a "no, never" option, a "don't know/can't remember" option, and an "other" fill-in option. For sources of information, the following specific sources were included as options: "campus organization," "university health center," "newspaper or magazine article," "other organization, such as the American Cancer Society," an "other" fill-in option, and a "cannot remember the source of information" option.

To provide indications of family health communication in general, participants were also asked to report on a 5-point scale of strongly agree to strongly disagree how influential they are to the family member participating in the study with them about health matters in general, and how comfortable they feel in talking about health matters with the family member participating in the study with them. Participants were asked to identify other family members with whom they discuss health, and were provided a checklist here as well as an "other" fill-in option.

To investigate the third research question, "what relationships, if any, exist among students' and their mothers' perceptions about breast cancer and reported family communication about breast cancer," statistical analyses of the above genetics and family communication items were conducted. The results of this analysis are presented in the following section. To investigate the fourth set of research questions related to sources of breast cancer information besides the mass media, participants were asked to check any sources of information that applied from the list provided. Options included various interpersonal sources (personal physician, physicians in general, other health professionals, friends, and relatives), books, scientific journals, campus organizations, and the internet, as well as "other" fill in and never options. Participants were asked to rank the

top three sources in terms of both importance and trustworthiness, were provided with the same checklist of topics used in preceding sections, and were asked how confident they are that the information they hear about these other sources is accurate, on a 5-point scale from "not at all confident" to "extremely confident."

To investigate the fifth and final research question regarding potential uncertainty management strategies reported by study participants, statistical analyses were conducted of the family communication and media exposure items described above. In addition, female participants were asked to report screening behaviors, including breast self-examination, clinical breast examination, and mammography.

CHAPTER 4

RESULTS

Focus Groups

The exploratory focus groups yielded beneficial information that assisted in the development and design of the survey instrument. Participants offered information about their perceptions about breast cancer and genetics, their experiences in talking about breast cancer with family and others, and recommendations related to the design and implementation of the questionnaire. As these groups were designed specifically to assist with the development of the survey and redundancy was not achieved due to their exploratory nature, formal analysis of the transcripts is not indicated. The moderator's guide and transcripts from these focus groups are included for review in Appendix B. Following are some key points generated by the focus groups that assisted in the development and administration of the survey:

- Participants consistently overestimated the role of genetics in the development of breast cancer, as expected. They also expressed confusion and uncertainty about the causes of breast cancer, and few had heard of BRCA genes.
- Participants discussed breast cancer topics they remembered seeing or hearing in the mass media, providing suggestions for specific areas to include in the survey.
- Participants shared a number of stories related to family communication about breast cancer, illustrating the importance of further examining this area of communication.

- Participants discussed their participation in activities such as Relay for Life and sorority distribution of shower cards, verifying that these on-campus activities merit further study.
- Male participants provided indications that they do attend to breast cancer information and discuss issues related to breast cancer with family members, suggesting it is important to include males in studies about breast cancer.

Survey of College Students and Their Mothers

Data were collected from a convenience sample of students from a large, introductory public relations course in the Fall of 2002. The initial data collection resulted in 217 student surveys (166 female students and 51 male students); the final sample, after repeated data collection efforts among students and their relatives and review of surveys for usability, includes 160 total usable student/mother pairs (128 female student/mother pairs, or 80%, and 32 male student/mother pairs, or 20%), resulting in a total N of 320. One hundred fifty-five adult female relatives reported being the mother of the student participating in the study with them, and 152 reported being biologically related to the student participant. All data reported in this section are taken from this final sample of college students and their mothers/adult female relatives.

Sample Characteristics of Students and Mothers

Given that the current study employed convenience sampling, statistical comparisons are not made between the study population and external populations, as generalizations to external populations are not appropriate with this method of sampling. However, this section includes information on external populations as well as the sample population to provide a context for the study's results.

Students. Thirty-two (20%) of the student participants identified themselves as male, and 128 (80%) of students identified themselves as female. In comparison, the overall student population of the University in which the study was conducted is 43% male and 57% female (SIRS, Fall 2002), while the College of Journalism and Mass Communication reports 73% of students are female and 27% are male. Therefore, the sample used for the current study includes disproportionately more female students than males in comparison with the overall student population and, while closer in proportion, also more female students than males in comparison to the College that offers the public relations course from which the current sample was drawn.

The mean age for students participating in this study is 20.29 (SD = 1.19); reported ages ranged from 18 to 24. One hundred two, or just over 63% of all student participants, reported an age within the range of 18-20, with the highest numbers of participants specifically reporting ages of 20 (57, or 35.6%), 19 (44, or 27.5%), and 21 (36, or 22.5%). In comparison with the University population, 42.9% of students fall in the 18-20 age range, while 36.9% of students in the College are within this range. Therefore, the study's sample is younger on average than the College and University from which the sample was drawn. Regarding race, the majority of student participants classified themselves as Caucasian (142 students, or 88.8%), followed by African-American (10 students, or 6.3%), Asian or Pacific Islander (4 students, or 2.5%), and Hispanic (2 students, or 1.3%). One student provided a racial classification of Multiracial, and one student provided a classification of Other Race.

Mothers. The mothers' reported ages ranged from 38 to 60, with most in the late 40s-early 50s. The mean age for mothers is 48.99 (SD = 4.36). With regard to race, mothers classified themselves as Caucasian (144, or 90%), African American (10, or 6.3%), Asian or Pacific Islander (3, or 1.9%), Hispanic

(2, or 1.3%), or Other Race (1, or 0.6%). While information was not obtained regarding participants' home state, 88.9% of the undergraduate population at this University is from the state of Georgia. Therefore, the researcher deemed it most useful to provide comparisons between the mothers and residents of this state.[2] With regard to age, the United States Census Bureau reports a median age of 34.7 for all women living in Georgia. An estimated 65.1% of Georgia residents are Caucasian, 28.7% are African American or Black, 2.2% are Asian or Pacific Islander, 5.3% are Hispanic, and 2.4% are some other race. Therefore, the study sample is much older than female Georgians on average (since the available census data includes all women, not just mothers of college students, this is to be expected) and includes disproportionately more Caucasians than among residents of the state in general.

In addition to the age and race questions, the mothers were asked to provide information related to their education and household income. Reported education of the mothers included high school diploma (19, or 11.9%), some college, with no degree awarded (25, or 15.6%), two-year college degree (17, or 10.6%), four-year college degree (51, or 31.9%), some post-graduate, no degree awarded (14, or 8.8%), and graduate degree (32, or 20.0%). Two mothers did not provide a response to this item. Therefore, most mothers reported having at least some college education, with 88.1% of participants reporting at least attending college and 71.3% of these reporting earning a degree of some kind. In comparison, census data for women over age 25 living in Georgia show only 48.1% having at least attended college, and just under 29% earning at least an associate degree or higher. Therefore, the sample

[2]All state population data were obtained from the United States Census Bureau, state-specific 2001 Supplemental Survey Summary Tables, located at http://factfinder.census.gov.

population is considerably higher in educational attainment than women 25 or older living in Georgia.

The sample mothers also appear to be much wealthier in general than residents of the University's home state. Only 13 participants (8.2%) reported an annual household income of less than $40,000 per year; in comparison, 46.5% of Georgians are estimated to have an annual household income of $40,000% or less. Of the 91.8% of participants whose household incomes are $40,000 or higher, 13 participants (8.1%) reported an income in the $40,000 to 59,999 range; 23 participants (14.4%) reported an income in both the $60,000-79,999 and $80,000-99,999 ranges, for a combined total of 46 participants (28.8%) reporting incomes between $60,000-99,999. Finally, 78 participants, or just under 49%, reported an annual household income of $100,000 or more.

Perceptions of Genetic Risk and Breast Cancer

To investigate the prediction that most participants will overestimate the role of genetics in the development of breast cancer, participants were asked to provide estimates of the chance a woman has of developing breast cancer in her lifetime, what percentage of all breast cancer cases are caused by a gene mutation, and the chance that women and men who carry a gene mutation associated with breast cancer will pass the gene on to any child they have. Their numeric responses to these questions were evaluated for correctness and assigned new variables to enable the researcher to calculate the number of participants who underestimated, overestimated, or accurately estimated each item. In addition, each participant was assigned a "score" of the number of correct responses to enable the researcher to conduct additional statistical analysis related to participants' perceptions of genetic risk and breast cancer.

The results of the single-sample chi square analyses for each of the items in this section are presented in Table 1.[3]

After a review of the literature on genetics and breast cancer, the following estimates were used as the "correct" estimates. The chance a woman has of developing breast cancer in her lifetime, according the National Cancer Institute, is 1 in 8 or 1 in 9, depending on the "end point" used to determine life expectancy (NCI Surveillance Program, SEER, 1988). Both of these estimates were coded as correct. The percentage of all breast cancer cases that are caused by a gene mutation is between 5 and 10%, according to Claus, Risch and Thompson, 1991 and Newman, Austin, Lee and King, 1988. Therefore, any estimate between 5 and 10% was coded as correct. Finally, the chance a man or woman has of passing a gene mutation associated with breast cancer to his or her child is 50% (Wonderlick & Fine, 1997).

Estimates of lifetime breast cancer risk. Based on the above criteria, only 13 participants, or 4%, correctly estimated a woman's chance of developing breast cancer in her lifetime; seven mothers and six students provided correct estimates. A comparison of individual students' and mothers' scores showed no student/mother pairs gave the correct response for this item. Many students and mothers underestimated lifetime risk; 137 (71 mothers and 66 students, or 42.8% of all participants) underestimated a woman's lifetime risk of developing cancer, while 170 participants (82 mothers and 88 students, or 46.9% of all participants) overestimated lifetime risk. Pearson chi square analysis of the entire group was significant, $(1, N = 320) = 270.11$, $p < .001$); additional analyses

[3] Independent sample t-tests were conducted prior to analysis to verify the appropriateness of treating mothers and students as single groups for the analyses related to H1. All tests showed the subgroups (mothers of males versus mothers of females, and male students versus female students) did not differ significantly in their total scores. T-tests were also conducted within the mothers group between mothers of males and mothers of females with regard to the demographic items; no significant differences were found. Therefore, the mothers were treated as one group for all analyses in the study.

showed no significant group association regarding estimates of lifetime risk (1, N = 320) = .08, Cramer's V = .02, p = .77).

Table 1. Estimations of Breast Cancer Risk, All Participants, N = 320

Item (correct response in parentheses)	Underestimated		Correct		Overestimated		Total
	n	%	n	%	n	%	
1. Woman's lifetime risk (1 in 8 or 9)	137	42.8	13	4.1	170	53.1	320
2. Breast cancers caused by gene (5-10%)	5	1.6	41	12.8	270	84.4	316
3. Woman's chance of passing on gene (50%)	140	43.8	105	32.8	75	23.4	320
4. Man's chance of passing on gene (50%)	212	66.3	78	24.4	27	8.4	317
Total	494		237		542		1273

NOTE: For all x^2 analyses, $p < .001$.

Estimates of percentage of cancers caused by a gene mutation. In contrast, in response to the question, "In your opinion, what percentage of all breast cancer cases are caused by a gene mutation," 270 participants, including 133 mothers and 137 students, provided a response that was higher than the correct estimate of 5 to 10%. Thus, 84.4% of those participating in the study overestimated the percentage of breast cancer cases caused by a gene mutation (Table 1). Two mothers and 3 students, or a total of 5 participants, provided estimates lower than 5%, while 22 mothers and 19 students, or 41 participants, provided an estimate within the range of 5 to 10%. A comparison of individual students' and mothers' scores showed that only 7 student/mother pairs (4.4%) provided the correct response to this item. Pearson chi square analysis of this item was also significant, (1, N = 318) = 181.13, p < .001), while again,

additional analysis showed no group association with estimated risk (1, N = 318) = .26, Cramer's V = .03, p = .61).

Estimates of the chance of a parent passing a breast cancer gene mutation on to his/her child. Participants were also asked to provide estimates of the chance that a man or woman has of passing a gene mutation associated with breast cancer on to his or her child. In general, participants' responses to these two items did not support the overall prediction that participants would overestimate the influence of genetics on the development of breast cancer (Table 1). Fifteen mother/student pairs (9.4%) provided correct estimates of a woman's chance, and 10 mother/student pairs (6.3%) provided correct estimates of a man's chance. Pearson chi square analyses of responses regarding both a woman's chance (1, N = 320) = 35.11, p < .001) and a man's chance (1, N = 316) = 83.05, p < .001) were significant. Additional analyses showed no significant group association with either item (woman's chance, Pearson x^2 (1, N = 320) = .69, Cramer's V = .05, p = .41; man's chance, Pearson x^2 (1, N = 316) = 1.55, Cramer's V = .07, p = .21).

Genetics and breast cancer knowledge scores. To further examine participants' perceptions of genetic risk for breast cancer, a score ranging from zero to 4 was computed for each participant based on their responses to the items above. Most participants scored 2 or lower, meaning that they provided correct responses to 2 or less of the items above. No students received a score of 4, while only one mother provided correct responses to all 4 items. The mean score for mothers was .81 (SD = .91); the mean score for students was .68 (SD = .75). While mothers scored slightly higher than students on average, an independent sample t-test showed the difference was not significant at the .05 level (p = .18). When comparing specific mothers and students, no mother/student pairs received a knowledge score of 3 or higher. Twenty-two

pairs (13.8 %) provided a correct response to one item, and just 5 mother/student pairs provided correct responses to two of the four knowledge items. The scores for individual participants are summarized in Table 2.

Participants' reported hearing of any BRCA gene. While not considered an indication of participants' actual knowledge about genetics, to provide a general measure of awareness or exposure to information about genetics and breast cancer, participants were asked if they had "ever heard of a gene called BRCA1, BRCA2, or BRCA3." Only 31, or 19.4%, of mothers reported hearing of a BRCA gene; just 5 female students, or 3.9%, reported hearing of a BRCA gene; and only one male student (3.1%) reported hearing of a BRCA gene. In sum, only 37 participants, or 11.6% of the total sample, reported ever hearing of a BRCA gene.

Table 2. Participants' Genetics and Breast Cancer Knowledge Scores, N = 320

Number of Items Correct (__/4)	Mothers		Students		
	n	%	n	%	Total
0	77	48.1	77	48.1	154
1	43	26.9	58	36.3	101
2	35	21.9	24	15.0	59
3	4	2.5	1	.6	5
4	1	.6	0	--	1
Total	160		160		320

Numeracy issues observed in participants' risk estimates. While not part of the planned design or analysis for this project, upon initial review of the data, the researcher noted one of the survey items designed to capture participants' estimates of genetic risk and breast cancer provided an illustration of low

numeracy, similar to the problems observed by Woloshin et al. (2001). This item, taken from Wonderlick and Fine's 1997 study, asks, "In your opinion, what is the chance for any woman to develop breast cancer during her lifetime," and offered participants the option to either provide their estimate as a ratio ("1 in ___") or state as a percentage. Preliminary analysis showed 86 participants, or just under 27% of all participants, provided a response to both options.[4] Of these, 50 participants, (58% of those providing both estimates, and 15.6% of the total sample), provided responses that were mathematically inconsistent. For example, a participant might give a ratio of 1 in 20 (or 5%) but also provide a percentage of 20%. While more than half of participants who provided both responses gave inconsistent responses, the difference between the two groups (consistent versus inconsistent responses) was not significant at the .05 level (Pearson $\underline{x}^2$ (1, N = 86) = 2.28, $\underline{p}$ = .13).

In addition, the distributions of responses to the numeric risk estimates for this same item, instead of being normally distributed around the correct answers, were concentrated instead around numbers such as 5, 10, and 20 (Figures 1 and 2). These distributions further illustrate potential numeracy issues, where participants may have simply provided a "round" number as a best guess.

[4] Since the two responses were designed to capture one answer, to enable inconsistent responses to be included in additional analyses, the researcher coded the higher of the two estimates as the response for the single item.

Figure 1. Ratio Estimates of Lifetime Breast Cancer Risk (N = 308)

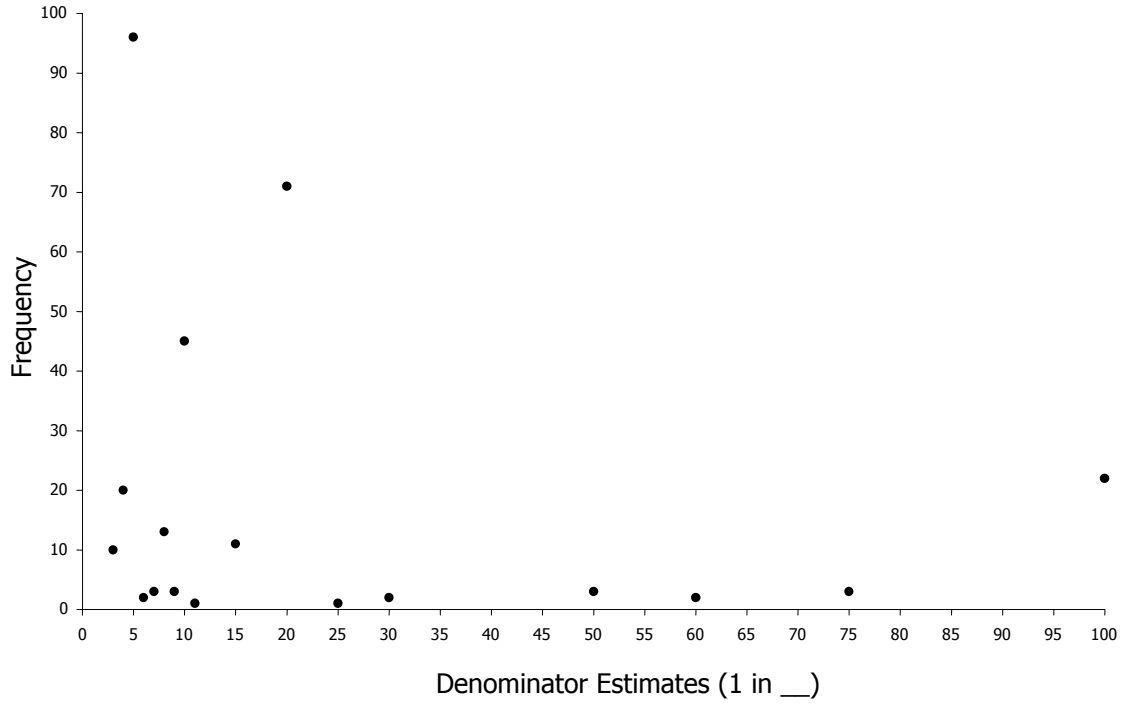
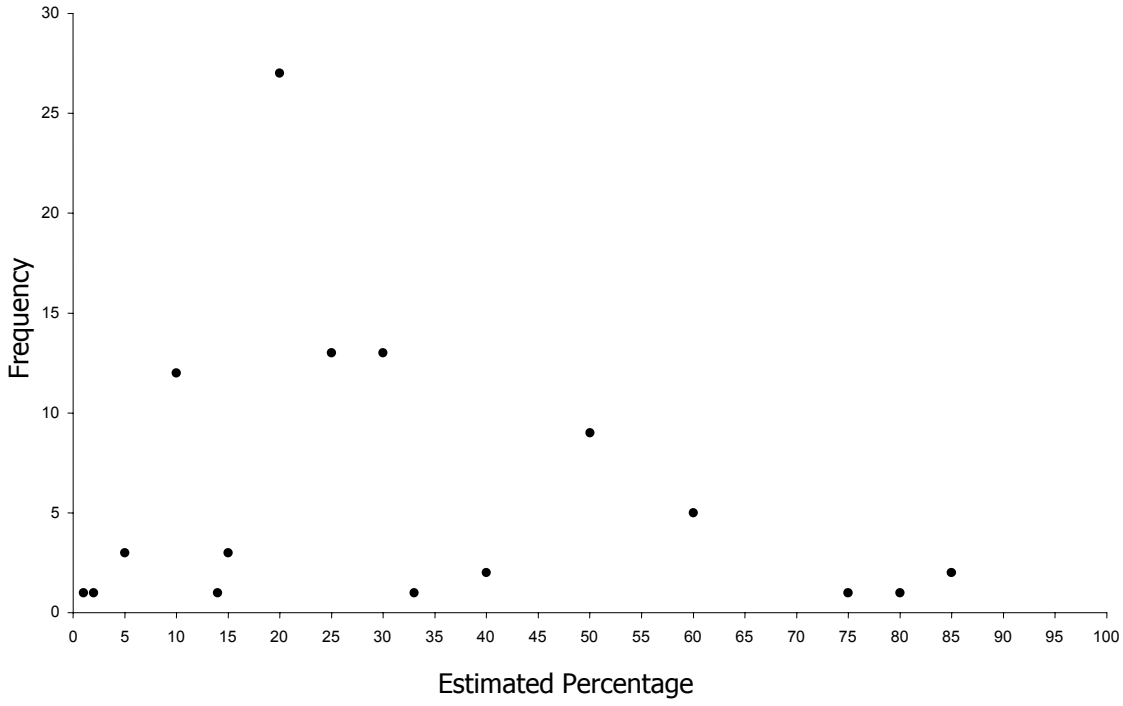


Figure 2. Percentage Estimates of Lifetime Breast Cancer Risk (N = 98)



Breast Cancer Information in Newspapers and Magazines

To investigate print media (magazines and newspapers) topics and sources, participants were asked about the frequency in which they read about breast cancer in newspapers and magazines, the kinds of topics they remember reading about, and specific sources of information. Participants were also asked to rate the accuracy and importance of the mass media in providing information about breast cancer. To assess the potential for group differences in responses, Pearson chi square analyses and independent sample t-tests were conducted.

Frequency and topics of breast cancer information in print media. First, participants were asked to indicate whether they never (0), seldom (1), sometimes (2), or frequently (3) read about breast cancer in newspapers or magazines. Sixteen participants, or 5%, reported never; 58, or 18.1%, reported seldom; 151 participants, or 47.2%, reported sometimes; and 95 participants, or 29.7% of the total sample, reported frequently reading about breast cancer in newspapers or magazines, resulting in a mean frequency of 2.02 (SD = .66).

To compare the responses of mothers and students on this item, analyses were conducted of the mean ratings provided for each group. When comparing mothers to students, the mothers' average reported frequency of reading about breast cancer is 2.31 (SD = .66); students' average reported frequency is 1.73 (SD = 0.87). This difference is significant at the .05 level ($p < .001$). Among students, the mean frequency with which male students reported reading about breast cancer is 1.13 (SD = .87); the mean frequency with which female students reported reading about breast cancer is 1.88 (SD = .8). Analysis revealed that the difference in reported frequency of the male and female students is also significant ($p < .001$).

To provide information about breast cancer information in newspapers and magazines, participants were asked to check specific topic(s) they

remembered reading. Participants could check up to nine categories from the provided list. Analyses revealed that mothers checked a significantly higher number of topics than students ($p < .001$): mothers checked an average of 5.59 topics ($SD = 1.85$), compared to students, who checked an average of 4.32 topics ($SD = 1.63$). While female students checked more topics on average ($M = 4.41$, $SD = 1.68$) than males ($M = 3.78$, $SD = 1.24$), the difference was not significant at the .05 level ($p = .086$). However, a separate analysis comparing all women (mothers and students) with the male students showed females checked an average of 5.08 topics ($SD = 1.87$), a significant difference ($p = .009$).

Regarding the individual categories, the most commonly read topics among mothers were breast cancer of a celebrity and breast cancer screening recommendations. Each of these was indicated by 148, or 92.5%, of the mothers. The next most commonly reported topics include breast cancer of a person other than a celebrity (141, or 88.1%), issues regarding effectiveness of breast cancer screening practices (135, or 84.4%), and environmental factors related to breast cancer (100, or 62.5%). The most commonly reported topics by female students include breast cancer screening recommendations (114, or 89.1%), issues regarding effectiveness of breast cancer screening practices (101, or 78.9%), breast cancer of a person other than a celebrity (100, or 78.1%), and breast cancer of a celebrity (96, or 75%). Male students reported breast cancer of a celebrity most frequently (21, or 65.6%), followed by breast cancer screening recommendations (16, or 50 %), breast cancer of a person other than a celebrity (15, or 46.9%), and issues regarding effectiveness of breast cancer screening practices (14, or 43.8%). Table 3 provides a summary of topics reported by group.

Table 3. Print Media Topics Reported by Mothers and Students, N = 320

Topic	Mothers (n=160) Rank(f)	%	Female Students (n=128) Rank(f)	%	Male Students (n=32) Rank(f)	%
Breast cancer of a celebrity	1(148)	92.5*	4(96)	75.0	1(21)	65.6
Breast cancer screening recs	1(148)	92.5	1(114)	89.1***	2(16)	50.0
Breast cancer of a non-celebrity	3(141)	88.1**	3(100)	78.1	3(15)	46.9
Effectiveness of screening practices	4(135)	84.4	2(101)	78.9****	4(14)	43.8
Environmental factors	5(100)	62.5*	5(52)	40.6	5(11)	34.4
Role of genes in breast cancer	6(78)	48.8*	6(29)	22.7	6(5)	15.6
Stories of women w/genetic mutation	7(75)	46.9*	7(24)	18.8	8(1)[1]	3.1
Statistics on genetics and breast cancer	8(47)	29.4**	8(18)	14.1	7(4)[1]	12.5
Some other topic on breast cancer	9(16)	10.0**	9(5)	3.9	9(0)[1]	--

*proportion sig. more than students; p < .001.
**proportion sig. more than students; p < .05.
***proportion sig. more than male students; p < .001.
****proportion sig. more than male students; p = .017.
[1] Cell n < 5, a violation of x^2 assumptions.

To identify possible group associations related to participants' responses, Pearson chi square analyses were conducted. Analyses of mothers and students (1, N = 304) revealed mothers identified the following topics in statistically higher proportions than students: breast cancer of a celebrity (Pearson x^2 = 10.41, Cramer's V = .18, p = .001), breast cancer of a person other than a celebrity (Pearson x^2 = 5.01, Cramer's V = .13, p = .025), stories about women who had a gene that predisposed them to breast cancer (Pearson x^2 = 30.77, Cramer's V = .32, p < .001), statistics about how often genes cause breast

cancer (Pearson x^2 = 8.95, Cramer's V = .17, p = .003), stories about how genes play a role in breast cancer (Pearson x^2 = 21.37, Cramer's V = .27, p < .001), environmental factors related to breast cancer (Pearson x^2 = 11.53, Cramer's V = .2, p = .001), and the "other topic" category (Pearson x^2 = 5.16, Cramer's V = .13, p = .023).

Significant group association was found with the male and female students (1, N = 145) on two topics: female students reported reading significantly more about breast cancer screening recommendations (Pearson x^2 = 11.9, Cramer's V = .29, p = .001) and issues regarding effectiveness of breast cancer screening practices (Pearson x^2 = 5.67, Cramer's V = .2, p = .017) than males. When comparing all female participants with males, Pearson chi square analyses (1, N = 304) show women indicated the following topics in statistically higher proportions: breast cancer of a person other than a celebrity (6.75, Cramer's V = .15, p = .009), breast cancer screening recommendations (15.23, Cramer's V - .22, p < .001), issues related to breast cancer screening practices (7.78, Cramer's V = .16, p = .005), and stories about women who had a gene that predisposed them to breast cancer (9.19, Cramer's V = .17, p = .002).

Print media sources of breast cancer information. Participants were also asked to provide information regarding specific newspapers and magazines in which they remembered reading about breast cancer. Nine categories plus a "don't know/can't remember" option were provided, for a total of 10 possible choices. Mothers reported an average of 3.47 individual sources (SD = 1.36), significantly higher than the average number of sources identified by students (M = 2.84, SD = 1.34, p < .001). When looking at the students, female students reported an average of 2.88 sources (SD = 1.38), compared to 2.7 sources reported on average by male students (SD = 1.15). This difference is not significant at the .05 level (p = .57). When comparing the mean number of

sources indicated by all women participating in the study (mothers and students) with males, the average number of sources reported by all females is 3.21 (SD = 1.4). While higher than the mean number of sources (2.7) reported by males, this difference is also not statistically significant at the .05 level (p = .09).

The four print media sources most commonly indicated by mothers and female students were directly parallel in terms of the ordering of frequencies and percentages within each group. The most frequently checked source of breast cancer information for both groups was women's magazines (mothers, 138, or 86.3%; female students, 105, or 82%), followed by news magazines (mothers, 93, or 58.1%; female students, 49, or 38.3%), the Atlanta Journal-Constitution (mothers, 90, or 56.3%; female students, 40, or 31.3%), and other hometown or local newspaper (mothers, 73, or 45.6%; female students, 33, or 25.8%). The student newspaper was the fifth most commonly indicated source among female students (32, or 25%). Male students most frequently reported reading about breast cancer in news magazines (15, or 46.9%), followed by the Atlanta Journal-Constitution (12, or 37.5%), national newspapers (10, or 31.3%), organizational magazines and other news magazines (9 responses, or 28.1% each). Table 4 includes frequency distributions for all 10 categories of newspaper and magazine sources reported by the mothers, female students, and male students.

Table 4. Print Media Sources Reported by Mothers and Students, N = 320

Source	Mothers (n=160) Rank(f)	%	Fem. Students (n=128) Rank(f)	%	Male Students (n=32) Rank(f)	%
Atlanta Journal-Constitution	3(90)	56.3*	3(40)	31.3	2(12)	37.5
Other major city newspaper	6(37)	23.1	7(19)	14.8	6(6)	18.8
Natl. newspaper, such as USA Today	5(51)	31.9	6(24)	18.8	3(10)	31.3*****
Other city/county newspaper	4(73)	45.6**	4(33)	25.8	6(6)	18.8
Red & Black student newspaper	9(1)[1]	0.6	5(32)	25.0	6(6)	18.8
Women's mag., such as Glamour	1(138)	86.3**	1(105)	82.0***	9(4)[1]	12.5
News mag., such as Newsweek	2(93)	58.1**	2(49)	38.3	1(15)	46.9*****
Organizational magazine	8(14)	8.8	8(18)	14.1****	4(9)	28.1
Some other newspaper/mag.	6(37)	23.1**	9(14)	10.9	4(9)	28.1

*proportion sig. more than students; p < .001.
**proportion sig. more than students; p <.01.
[1] Cell n < 5, a violation of x^2 assumptions.
***proportion sig. more than male students; p <.001.
****proportion sig. more than male students; p < .05.
*****proportion sig. more than female students; p <.05.

Pearson chi square analyses (1, N = 303) comparing mothers and students show mothers were significantly higher in proportion on the following: the Atlanta Journal-Constitution (13.52, Cramer's V = .21, p < .001), hometown/local newspaper (12.1, Cramer's V = .2, p = .001), women's magazines (7.43, Cramer's V = .16, p = .006), news magazines (6.56, Cramer's V = .15, p = .01), and other newspaper or magazine (10.23, Cramer's V = .18, p = .001). Students reported significantly higher readership of the Red and Black student newspaper (44.1, Cramer's V = .38, p < .001).

Pearson chi square analyses on male and female students (1, N = 145) yielded significant group associations on the following print media sources: male students read proportionately more about breast cancer than females in national newspapers (6.11, Cramer's V = .21, p = .013) and news magazines (4.93, Cramer's V = .18, p = .026), while a significantly higher proportion of females reported reading breast cancer information in organizational magazines (3.87, Cramer's V = .16, p = .049) and women's magazines (48.9, Cramer's V = .58, p < .001) than males. Finally, Pearson chi square analyses (1, N = 303) comparing the responses of all female participants (mothers and students) with males revealed significant group associations on the following sources: proportionately more males than females reported the Red and Black student newspaper (3.88, Cramer's V = .11, p = .049); proportionately more females than males reported women's magazines (67.94, Cramer's V = .47, p < .001) and some other newspaper or magazine (5.04, Cramer's V = .13, p = .025).

Accuracy ratings of breast cancer information in print media. The final questions in this area asked participants to provide their perceptions regarding the accuracy of breast cancer information in newspapers and magazines, on a scale ranging from not at all confident (0) to extremely confident (4).[5] For newspapers, mothers provided a mean accuracy rating of 2.75 (SD = .8); students provided a mean accuracy rating of 3.14 (SD = .44). An independent samples t-test showed this difference is significant at the .05 level (p < .001). Students also rated magazines significantly higher (p < .001) in perceived accuracy than their mothers; according to an independent samples t-test, students' mean accuracy rating for the information they read in magazines is 3.21 (SD = .48), compared to the mothers' average score of 2.89 (SD = .69; see

[5] Participants were also given the option to indicate that they had not read about breast cancer in newspapers or magazines. These responses were excluded from the comparison of means analysis.

Table 7 for a summary of the mean accuracy ratings for newspapers, magazines, and television).

Breast Cancer Information on Television

To investigate television topics and sources, participants were asked about the frequency in which they saw or heard about breast cancer on television, the kinds of topics they remember hearing or seeing, and specific sources of information. Participants were also asked to rate the accuracy and importance of televised sources in providing information about breast cancer. To statistically assess the potential for group differences in responses, Pearson chi square analyses and independent sample t-tests were conducted.

Frequency and topics of breast cancer information on television. First, participants were asked to indicate whether they never (0), seldom (1), sometimes (2), or frequently (3) saw or heard about breast cancer on television. Four mothers (2.5%) reported never hearing about breast cancer on television; 16 (10%) reported seldom hearing about breast cancer on television; 76 (47.5%) reported sometimes hearing about breast cancer on television; and 63 (39.4%) reported frequently hearing about breast cancer on television. Nine female students (7%) reported never hearing about breast cancer on television; 27 (21.1%) reported seldom hearing about breast cancer on television; 60 (46.9%) reported sometimes hearing about breast cancer on television; and 32 (25%) reported frequently hearing about breast cancer on television. Finally, with regard to the male students, 3 students (9.4%) reported never hearing about breast cancer on television, while 12 (37.5%), 15 (46.9%), and 2 (6.3%) male participants reported seldom, sometimes, and frequently hearing about breast cancer on television, respectively.

In comparing means of the frequencies reported by participants with regard to their exposure to breast cancer information on television, independent

samples t-tests showed mothers' average frequency, 2.31 (SD = .74), is significantly higher than that of the students (M = 1.82, SD = .85, p < .001). In addition, the average reported frequency of female students (M = 1.9, SD = .86) is significantly higher than that of the male students (M = 1.5, SD = .76, p < .001).

As with newspapers and magazines, participants were asked to identify specific breast cancer topics they had seen or heard on television. Of the nine topic categories, mothers reported an average of 4.97 topics (SD = 1.97), while students identified an average of 3.88 (SD = 1.68). Based on independent samples t-tests, this difference is significant at the .05 level (p < .001). While female students provided slightly more topics on average (M = 3.99, SD = 1.74) than males (M = 3.41, SD = 1.32), the difference was not statistically significant (p = .097). However, when comparing all female participants (mothers and students) with the male students, the average number of topics checked by all females (M = 4.55, SD = 1.94) was significantly higher (p = .002).

The breast cancer topics mothers most commonly reported hearing on television were breast cancer of a celebrity (149, or 93.1%), breast cancer screening recommendations (131, or 81.9%), breast cancer of a person other than a celebrity (128, or 80%), and issues related to breast cancer screening practices (125, or 78.1%). Female students reported the same topics as their mothers the most frequently, and in the same order: breast cancer of a celebrity (103, or 80.5%), breast cancer screening recommendations (99, or 77.3%), breast cancer of a person other than a celebrity (91, or 71.1%), and issues related to breast cancer screening practices (87, or 68%). Male students reported hearing most frequently about the same four topics on television as female students and mothers, but the percentages were slightly different: males also reported hearing about breast cancer of a celebrity most frequently on

television (24, or 75%), but they reported hearing about screening recommendations and issues regarding breast cancer screening practices equally (19, or 59.4%, each), while 16 males, or 50%, reported hearing about breast cancer of a person other than a celebrity on television. Frequency distributions of all topics reported by mothers, female students, and male students are presented in Table 5.

To determine if reported television topics were significantly associated with mothers and students, Pearson chi square analysis (1, N = 304) was conducted on each topic. Mothers reported significantly higher proportions than students on the following topics: breast cancer of a celebrity (8.55, Cramer's V = .17, p = .003), breast cancer of a person other than a celebrity (4.12, Cramer's V = .12, p = .042), stories about women who had a gene that predisposed them to breast cancer (18.8, Cramer's V = .25, p < .001), stories about how genes play a role in breast cancer (19.5, Cramer's V = .25, p < .001), and environmental factors related to breast cancer (17.08, Cramer's V = .24, p < .001). When comparing female students and male students, female students' proportions were significantly higher than males on two topics: breast cancer of a person other than a celebrity (Pearson x^2 (1, N = 148) = 5.28, Cramer's V = .19, p = .022) and breast cancer screening recommendations (Pearson x^2 (1, N = 148) = 4.51, Cramer's V = .18, p = .034).

Finally, comparisons (1, N = 304) of all female participants (mothers and students) with males revealed significance on three topics. Males reported a significantly higher proportion on the topic of breast cancer of a person other than a celebrity (Pearson x^2 = 8.95, Cramer's V = .17, p = .003), while females reported significantly higher proportions on breast cancer screening recommendations (Pearson x^2 = 5.81, Cramer's V = .14, p = .016) and stories

about women who had a gene that predisposed them to breast cancer (Pearson $\underline{x}^2 = 6.89$, Cramer's $\underline{V} = .15$, $\underline{p} = .009$).

Table 5. Television Topics Reported by Mothers and Students, $\underline{N} = 320$

Topic	Mothers (n=160) Rank(f)	%	Female Students (n=138) Rank(f)	%	Male Students (n=32) Rank(f)	%
Breast cancer of a celebrity	1(149)	93.1**	1(103)	80.5	1(24)	75.0
Breast cancer screening recs	2(131)	81.9	2(99)	77.3***	2(19)	59.4
Breast cancer of a non-celebrity	3(128)	80.0	3(91)	71.1***	4(16)	50.0
Effectiveness of screening practices	4(125)	78.1	4(87)	68.0	2(19)	59.4
Environmental factors	5(84)	52.5*	5(36)	28.1	5(9)	28.1
Role of genes in breast cancer	7(58)	36.3*	7(17)	13.3	6(5)	15.6
Stories of women w/genetic mutation	6(60)	37.5*	6(22)	17.2	8(2)[1]	6.3
Statistics on genetics and breast cancer	8(32)	20.0	7(17)	13.3	7(4)[1]	12.5
Some other topic on breast cancer	9(9)	5.6	9(3)[1]	2.3	9(1)[1]	3.1

*proportion sig. more than students; $p < .001$.
**proportion sig. more than students; $p < .05$.
***proportion sig. more than male students; $p < .05$.
[1] Cell $\underline{n} < 5$, a violation of x^2 assumptions.

Television sources of breast cancer information. Mothers reported an average of 3.5 specific television sources ($\underline{SD} = 1.34$); students reported an average of 3.0 sources ($\underline{SD} = 1.19$). This difference is significant ($\underline{p} = .001$). In contrast, when comparing male and female students, females reported just over three sources ($\underline{M} = 3.04$, $\underline{SD} = 1.25$); while somewhat higher than the average

number of sources reported by males (M = 2.86, SD = .92), the difference was not significant at the .05 level (p = .47).

With regard to specific television sources of breast cancer information, national news was the top source (143, or 89.4%) indicated by mothers, followed by local news (131, or 81.9%), cable or satellite programs (90, or 56.3%), and national programming other than news (79, or 49.4%). Female students indicated local news (86, or 67.2%), national news (85, or 66.4%), cable or satellite programs (80, or 62.5%), and national programming other than news (44, or 34.4%) most frequently. Male students checked local news and national news most frequently (26, or 81.3%, each), followed by cable or satellite programs and national programming other than news (10, or 31.3%, each). Table 6 provides a summary of reported television sources by group.

To identify group association with reported television sources, Pearson chi square analyses with mothers and students (1, N = 304) were conducted. Mothers reported the following television sources in significantly higher proportions: national news (15.35, Cramer's V = .23, p < .001), national programming other than news (6.18, Cramer's V = .14, p = .013), public broadcasting (9.839, Cramer's V = .18, p = .002); students reported they could not remember the specific television source of breast cancer information in significantly higher proportions than mothers (8.87, Cramer's V = .17, p = .003). Among students, according to Pearson chi square analyses (1, N = 148), females reported local news (3.83, Cramer's V = .16, p = .05), national news (4.13, Cramer's V = .17, p = .042), and cable or satellite (10.49, Cramer's V = .27, p = .001) in more significant proportions than males. When comparing all female participants with males, the women reported cable or satellite as a specific television source of breast cancer information in significantly higher proportions

(Pearson chi square (1, N = 304) = 8.12, Cramer's V = .16, p = .004) than males.

Table 6. Television Sources Reported by Mothers and Students, N = 320

Source	Mothers		Female Students		Male Students	
	Rank(f)	%	Rank(f)	%	Rank(f)	%
Local news	2(131)	81.9	1(86)	67.2	1(26)	81.3
National news	1(143)	89.4*	2(85)	66.4***	1(26)	81.3
Local programming other than news	6(42)	26.3	5(24)	18.8	5(5)	15.6
Natl. programming other than news	4(79)	49.4**	4(44)	34.4	3(10)	31.3
Public broadcasting	5(48)	30.0**	6(19)	14.8	6(4)[1]	12.5
Cable or satellite programming	3(90)	56.3	3(80)	62.5***	3(10)	31.3
Some other television source	7(7)	4.4	7(6)	4.7	7(0)[1]	--

*proportion sig. more than students; p < .001.
**proportion sig. more than students; p < .05.
***proportion sig. more than male students; p < .05.
[1] Cell n < 5, a violation of x^2 assumptions.

Accuracy of breast cancer information on television. Finally, participants were asked to rate how confident they are that the information they hear about breast cancer on television is accurate, on a scale of zero (not at all confident that the information is accurate) to four (extremely confident that the information is accurate).[6] Mothers provided a mean rating of 2.83 (SD = .73); students provided a mean rating of 3 (SD = .57). This difference is significant at the .05 level (p = .027). Among students, female students' average perceived accuracy of television (M = 3.02, SD = .58) was slightly higher than the males (M = 2.9, SD = .56), but the difference is not statistically significant at the .05

[6] Participants were also given the option to indicate that they had not heard about breast cancer on television. These responses were excluded from the comparison of means analysis.

level (p = .28). The mean accuracy ratings for newspapers, magazines, and television are presented for comparison in Table 7.

Table 7. Mean Accuracy Ratings[1] for Mass Media Sources by Group, N = 320

Media Source	Mothers		Students	
	M	SD	M	SD
Newspapers	2.75*	.80	3.14	.44
Magazines	2.89*	.69	3.21	.48
Television	2.83**	.73	3.00	.57

*significantly lower than students; p < .001.
**significantly lower than students; p = .027.
[1] Accuracy rated on a scale of 0-4, where 4 represents "extremely confident that the information is accurate."

Family Communication and Breast Cancer

To investigate questions regarding family communication about breast cancer, participants were asked to provide responses to several items intended to identify the frequency and types of family health communication, specific family members with whom participants discuss health, and participants' perceptions regarding their influence and comfort in discussing health with family members. As with the mass media items, Pearson chi square analyses and independent sample t-tests were conducted to analyze responses to these items.

Frequency and topics of breast cancer family communication. First, participants were asked to rate the frequency with which they discuss issues related to breast cancer with the family members participating in the study with them, on a scale from never (0) to every day (5). Mothers reported a mean frequency of 1.23 (SD = .96); students reported a mean frequency of 1.25 (SD = .99). In other words, mothers and students alike reported an average of just over one or two times total; the difference in means is not significant (p = .87). In contrast, when looking at female students compared to male students, the

average frequency with which female students reported discussing breast cancer with family members is 1.33 (SD = .96), compared to the average frequency of .47 (SD = .76) reported by male students, a significant difference ($p < .001$). When comparing all females (mothers and students) with the male students, females reported on average a frequency of 1.45 (SD = .95); this average is also significantly higher than that of the male students ($p < .001$).

Regarding specific breast cancer topics discussed with family members, mothers indicated an average of 2.38 topics (SD = 1.32), while students indicated an average of 2.5 topics (SD = 1.2). This difference is not statistically significant at the .05 level ($p = .41$). Male students provided an average number of topics that was slightly lower (M = 2.08, SD = 1.16) than the average numbers provided by all females participating in the study (M = 2.46, SD = 1.26) as well as female students specifically (M = 2.56, SD = 1.19). However, neither difference is significant at the .05 level ($p = .31$ and $p = .2$, respectively).

To look at the possibility of group associations with individual family communication topics, Pearson chi square analyses (1, N = 240, P = .05) were conducted for each of the seven topics. First, comparisons were made between mothers and students. Analyses revealed that students and mothers did not differ significantly in the proportion of their responses to any of the family communication topics. Additionally, males and females did not differ significantly in the proportion of family communication topics, nor did female students and males.[7] Therefore, family communication topics are reported with regard to the entire study population; see Table 8.

[7] Among the students, one topic, breast cancer screening, approached significance at the .05 level (Cramer's V = .18, p = .054).

Table 8. Reported Family Communication Topics, All Participants, N = 320

Topic (in order of frequency reported)	f	%
1. Breast cancer screening recommendations	170	53.1
2. Breast cancer of a friend	142	44.4
3. Breast cancer of a family member	126	39.4
4. Genetic factors related to breast cancer	53	16.6
5. Environmental factors related to breast cancer	45	14.1
6. Breast cancer of a celebrity	41	12.8
7. Some other topic about breast cancer	9	2.8
Total	586[1]	

[1] Note: number of topics is greater than N due to ability for individual participants to indicate more than one topic.

Specific family members included in family communication about health. Participants were also asked to provide information regarding specific family members with whom they discussed health, in addition to the family members participating in the study with them. Because of the obvious likelihood for group association with some family members (i.e., mothers will report sons, daughters, and spouses in higher proportions than students), chi square analyses by group are not reported. In sum, mothers reported discussing health most frequently with spouses (122, or 76.3%), followed by sisters (89, or 55.6%), daughters (86, or 53.8%), sons (58, or 36.3%), some other family member (54, or 33.8%), brothers (39, or 24.4%), fathers (34, or 21.3%), aunts or uncles (25, or 15.6%), and grandparents (24, or 15%).

Female students reported most frequently discussing health with fathers (66, or 51.6%), followed by sisters (42, or 32.8%), grandparents (40, or 31.3%), aunts or uncles (35, or 27.3%), and brothers (22, or 17.2%). Males reported most frequently discussing health with fathers (23, or 71.9%), followed by

grandparents (11, or 34.4%), brothers (9, or 28.1%), sisters (6, or 18.8%), and aunts or uncles (4, or 12.5%).[8]

Perceptions about family communication and health. To assess perceptions related to perceived influence and comfort in discussing health with family members, participants were asked to provide a response on a 5-point scale, from "strongly disagree (1)" to "strongly agree (5)," to the following items: "I feel that I am an influential source of information about health matters in general to the family member participating in the study with me," and, "I feel comfortable talking about health matters in general with the family member participating in the study with me." Table 9 summarizes the results of the independent samples t-tests of these two items.

Table 9. Ratings of Influence and Comfort[1] in Discussing Health with Family, All Participants, N = 320

Item	Mothers		Students	
	M	SD	M	SD
I feel that I am an influential source of information about health matters in general to the family member participating in the study with me.	4.29*	.88	2.99	1.16
I feel comfortable discussing health matters in general with the family member participating in the study with me.	4.74	.60	4.58	.84

*significantly higher than students; $p < .001$.
[1] Ratings on a scale from 1-5, where 5 = "strongly agree."

Family communication and genetics knowledge. The third research question in the present study sought to investigate possible relationships between participants' genetic knowledge responses and frequency of family communication. Responses to the genetics and breast cancer items were

[8] It is important to note that participants were specifically asked to provide information on family members other than the student or mother participating in the study with them; thus, it should not be assumed, for example, that students discuss health matters with any of the family members listed here more than their mothers.

reviewed to determine the potential for statistically comparing participants' reported frequency of family communication with scores on the knowledge items presented above. However, since there was little variance in individual scores on the knowledge items (most participants scored a 1 or 2), and since additional analyses showed only five mother/student pairs scored a 2 out of a possible 4, with no pairs scoring higher than 2, it was determined that statistical analyses would not be appropriate as a method for examining this research question.

Instead, to provide a measure of effect size, or the strength of the relationship between row and column variables, the Cramer's Measure of Association statistic (Cramer's V), is provided with significant chi square analyses for all categorical variables. This statistic is a derivative of the Pearson product-moment correlation coefficient, is identical to phi for 2x2, 2x3, and 3x2 tables, and rescales phi when row and column variables have more than two levels so the values will range from zero to one to aid interpretation. For most analyses in the current study, "phi" and "Cramer's V" are interchangeable.

Traditionally, Cramer's V values of .10, .30, and .50 represent small, medium, and large effect sizes, respectively. These values should be used as benchmarks when interpreting the results of the current study. In addition, when row and column variables are qualitative, the sign is not meaningful, and any negative phi values can be changed to positive values without affecting their meaning. For consistency, in the present study, all Cramer's V statistics are reported as positive values (see Green, Salkind, and Akey, 1997, for a more thorough discussion of the phi and Cramer's V statistics).

Other Sources of Breast Cancer Information

Specific other sources of breast cancer information. The first item designed to capture information about sources other than the mass media and specific family members included interpersonal sources (medical professionals, friends, and relatives in general), print sources (books, scientific journals), organizational sources (campus organizations) and the Internet, as well as an "other" option. Among mothers, the most commonly identified source of breast cancer information was personal physician (148, or 92.5%), followed by friends (120, or 75%), relatives (96, or 60%), and other health professionals (74, or 46.3%). Among female students, the most frequently cited sources were relatives (90, or 70.3%), personal physician (84, or 65.6%), friends (69, or 53.9%), physicians in general (47, or 36.7%), and campus organizations (40, or 31.3%). Males cited relatives (14, or 43.8%) most frequently, followed by friends (11, or 34.4%), physicians in general (6, or 18.8%), and the Internet (5, or 15.6%). Twelve male participants, or 37.5%, reported they have never received information about breast cancer from other sources. Table 10 illustrates the frequency distributions for all categories of this item.

A comparison of means (independent samples t-test) for the number of sources indicated by participants shows mothers reported an average of 4.02 other sources (SD= 1.76), compared to an average 2.98 reported by students (SD = 1.88). This difference was statistically significant ($p < .001$). Female students reported an average of 3.37 sources (SD = 1.74), significantly higher than the average reported by the male students ($M = 1.43$, SD = 1.66, $p < .001$). All females reported an average of 3.73 sources (SD = 1.77), again, significantly higher than the males participating in the study.

Table 10. Other Sources of Breast Cancer Information Reported by Mothers and Students, N = 320

Source	Mothers		Female Students		Male Students	
	Rank(f)	%	Rank(f)	%	Rank(f)	%
Personal physician	1(148)	92.5*	2(84)	65.6***	10(0)[1]	--
Physicians in general	6(52)	32.5*	4(47)	36.7	3(6)	18.8
Health professionals	4(74)	46.3*	7(25)	19.5	6(3)[1]	9.4
Friends	2(120)	75.0*	3(69)	53.9****	2(11)	34.4
Relatives in general	3(96)	60.0	1(90)	70.3****	1(14)	43.8
Books	5(71)	44.4*	7(25)	19.5	8(2)[1]	6.3
Scientific journals	8(29)	18.1**	9(10)	7.8	9(1)[1]	3.1
Campus organization	10(1)[1]	0.6	5(40)	31.3****	6(3)[1]	9.4
Internet	7(44)	27.5	6(31)	24.2	4(5)	15.6
Some other source	9(8)	5.0	10(7)	5.5	9(1)[1]	3.1

*proportion sig. more than students; p < .001.
**proportion sig. more than students; p = .003.
***proportion sig. more than male students; p < .001.
****proportion sig. more than male students; p < .05.
[1] Cell n < 5, a violation of x^2 assumptions.

To investigate group associations among these "other source" categories, Pearson chi square analyses (1, N = 319) were conducted. When comparing mothers to students, mothers reported significantly higher proportions on the following: personal physician (63.27, Cramer's V = .45, p < .001), other health professionals (30.07, Cramer's V = .31, p < .001), friends (20.78, Cramer's V = .26, p < .001), books (28.12, Cramer's V = .3, p < .001), and scientific journals (9.13, Cramer's V = .17, p = .003). Students' proportions were significantly higher than mothers on campus organizations (46.81, Cramer's V = .38, p < .001) and never receiving information about breast cancer from other sources (17.4, Cramer's V = .23, p < .001).

Among students, Pearson chi square analyses (1, N = 159) revealed female students reported significantly higher proportions than males on personal

physician (44.87, Cramer's V = .53, p < .001), friends (4.07, Cramer's V = .16, p = .04), relatives (8.31, Cramer's V = .23, p = .004), and campus organizations (6.34, Cramer's V = .2, p = .012). A significantly higher proportion of male students than female students reported never receiving breast cancer information from other sources (24.9, Cramer's V = .4, p < .001).

Other source breast cancer topics. With regard to specific topics these other sources provide, participants were provided with the same list of nine categories provided for print media and television. Mothers reported a significantly higher number of topics (M = 4.35, SD = 2.03) than students (M = 3.41, SD = 1.59, p < .001); female students reported a significantly higher number of topics (M = 4.01, SD = 1.89) than male students (M = 2.44, SD = 1.34, p = .001). By group, the topics most often reported by mothers are screening recommendations (148, or 92.5%), followed by issues related to screening practices (136, or 85%), breast cancer of a person other than a celebrity (108, or 67.5%), and environmental factors related to breast cancer (86, or 53.8%).

Female students reported the same topics, and in the same proportions, as the mothers: screening recommendations (105, or 82%), issues regarding screening practices (91, or 71.1%), breast cancer of a person other than a celebrity (84, or 65.6%), and environmental factors related to breast cancer (46, or 35.9%). Among male students, most frequently cited topics in this area were breast cancer of a person other than a celebrity (12, or 37.5%), followed by breast cancer screening recommendations (8, or 25%), breast cancer of a celebrity (7, or 21.9%), screening practices and environmental factors related to breast cancer (5, or 15.6%, each). Table 11 provides a comparison of the responses of students and mothers for each topic category regarding breast cancer information provided by these "other" sources.

Table 11. Other Source Topics Reported by Mothers and Students, N = 320

Topic	Mothers		Female Students		Male Students	
	Rank(f)	%	Rank(f)	%	Rank(f)	%
Breast cancer of a celebrity	5(63)	39.4	5(35)	27.3	3(7)	21.9
Breast cancer screening recs	1(148)	92.5**	1(105)	82.0***	2(8)	25.0
Breast cancer of a non-celebrity	3(108)	67.5	3(84)	65.6	1(12)	37.5
Effectiveness of screening practices	2(136)	85.0**	2(91)	71.1***	4(5)	15.6
Environmental factors	4(86)	53.8**	4(46)	35.9	4(5)	15.6
Role of genes in breast cancer	6(62)	38.8*	7(23)	18.0	7(2)[1]	6.3
Stories of women w/genetic mutation	7(45)	28.1	6(26)	20.3****	9(0)[1]	--
Statistics on genetics and breast cancer	8(36)	22.5	8(15)	11.7	6(4)[1]	12.5
Some other topic on breast cancer	9(4)[1]	2.5	9(2)[1]	1.6	8(1)[1]	3.1

*proportion sig. more than students; p < .001.
**proportion sig. more than students; p < .01.
***proportion sig. more than male students; p < .001.
****proportion sig. more than male students; p = .028.
[1] Cell n < 5, a violation of x^2 assumptions.

To determine group associations, Pearson chi square analyses (1, N = 296) were conducted with mothers and students. According to these analyses, mothers reported a significantly higher proportion than students on the following topics: screening recommendations (9.81, Cramer's V = .18, p = .002), issues regarding screening practices (11.85, Cramer's V = .2, p = .001), stories about how genes play a role in the development of breast cancer (15.84, Cramer's V = .23, p < .001), and environmental factors related to breast cancer (9.05,

Cramer's V = .18, p = .003). Students did not report a higher proportion than mothers on any "other source" topics.

Among students, Pearson chi square analyses (1, N = 138) show a significantly higher proportion of women than men reported screening recommendations (Pearson x^2 = 19.6, Cramer's V = .38, p < .001), issues regarding screening practices (Pearson x^2 = 17.07, Cramer's V = .35, p < .001), and stories about women who had a gene that predisposed them to breast cancer (Pearson x^2 = 4.81, Cramer's V = .19, p = .028). When comparing the responses of all female participants (mothers and students) with the male students (1, N = 296), breast cancer screening recommendations (Pearson x^2 = 35.15, Cramer's V = .35, p < .001), issues regarding breast cancer screening practices (Pearson x^2 = 28.96, Cramer's V = .31, p < .001), and stories about women who had a gene that predisposed them to breast cancer (Pearson x^2 = 6.06, Cramer's V = .14, p = .014) were reported in significantly higher proportions by women compared to men.

Uncertainty Management Strategies

The final area of analysis examined participants' behaviors that can be interpreted as strategies to manage uncertainty related to breast cancer risk. While several of the above communication-related responses can be interpreted as uncertainty management behaviors, additional information regarding potential uncertainty management strategies was gathered. Specifically, female participants were asked about screening behaviors, student participants were asked about information about breast cancer they have provided to adult female relatives, and all participants (except for mothers of male students) were asked to report the frequency with which they have specifically recommended to the person participating in the study with them to have breast cancer screenings.

Finally, all participants were asked to report if they had participated in genetic testing or counseling for breast cancer.

Women's reported screening behaviors. With regard to female participants' screening behaviors, survey items included questions regarding breast self-examination, mammography, and clinical breast examination. Given that the categories provided are based on screening recommendations and are not of equal intervals, conducting a comparison of means is not appropriate; thus, frequencies of responses and Pearson chi square analyses are reported to illustrate the findings (results are summarized in Table 12).

Table 12. Female Participants' Reported Breast Cancer Screening, N = 288

	Mothers (n=160)		Daughters (n=128)		
Type of Screening Reported	f	%	f	%	Total
Breast self-examination:					
Monthly	78	48.8	26	20.3	104
Never	7	4.4	34	26.6	41
All other categories	73	45.6	66	51.6	139
Total BSE	158		126		284
Mammography:					
Annually	124	77.5	3	2.3	127
Never	6	3.8	112	87.5	118
All other categories	28	17.5	6	4.6	34
Total Mammography	158		121		279
Clinical breast examination:					
Annually	131	81.9	80	62.5	211
Never	0	--	26	20.3	26
All other categories	23	14.4	20	15.6	43
Total CBE	154		126		280

Note: for all screening categories, mothers reported significantly greater proportions; $p < .001$.

Among students, 34 female students, or 26.6%, reported never conducting breast self-examination; 20, or 15.6%, reported once a year or less; 45, or 35.2%, reported a few times a year; 26, or 20.3%, reported monthly; and

one participant, or .8% of all female students, reported conducting breast self-examination on a weekly basis. Among mothers, 7, or 4.4%, reported never conducting breast self-examination; 5, or 3.1%, reported once a year or less; 54, or 33.8%, reported a few times a year; 78, or 48.8%, reported monthly; and 14 mothers, or 8.8%, reportedly conduct breast self-examination weekly.[9]

All female participants were also asked to provide the number of times they have had mammograms (Table 12). Most mothers reported having a mammogram once a year (124, or 77.5%)[10]; of the remaining 22.5%, 8 mothers, or 5%, reported having one mammogram total; 8 mothers, or 5%, reported having one whenever recommended by their physicians; and the remaining three categories, once every two years, never, or other, were reported by 6 mothers, or 3.8%, each. Even though mammography is not generally indicated for women under 40 according to widely published guidelines by health agencies such as the American Cancer Society and National Cancer Institute, 5 female students reported having a mammogram one time, 3 indicated having one a year, and one female student indicated she had a mammogram once every two years.

Next, female participants were asked to provide the number of times they had clinical breast examinations (breast examinations performed by a health practitioner; see Table 12).[11] Mothers most often reported having a clinical breast examination once a year (131, or 81.9%), followed by once every two years (11, or 6.9%), other frequency (10, or 6.3%), and one total (2, or 1.3%). No mothers reported never having a clinical breast examination. The majority of

[9] The frequency with which breast self-examination is widely recommended by health agencies at the present time is once a month for all women 18 and older.
[10] Once a year is the guideline for screening mammography generally recommended for women 40 and older.
[11] Once a year is the guideline for clinical breast examination generally recommended for women 18 and older.

female students also reported having a clinical breast examination once a year; eighty female students, or 62.5%, reported having a clinical breast examination once a year, while the remaining 37.5% reported having one time total (15, or 11.7%), once every two years (2, or 1.6%), some other frequency (3, or 2.3%), or never (26, or 20.3%).

Pearson chi square analyses were conducted on the above behavioral items to identify possible group associations related to proportions of responses for each category, and revealed all three items were significant[12]: for breast self-examination, $\underline{x}^2$ (4, $\underline{N}$ = 284) = 62.05, Cramer's $\underline{V}$ = .47; for mammography, $\underline{x}^2$ (5, $\underline{N}$ = 281) = 223.5, Cramer's $\underline{V}$ = .89[13]; and for clinical breast examination, $\underline{x}^2$ (4, $\underline{N}$ = 280) = 56.03, Cramer's $\underline{V}$ = .45; for all analyses, $\underline{p} < .001$).

Genetic counseling and testing. It was hoped that at least some participants would report participating in genetic counseling and/or testing for breast cancer; however, no participants indicated they had participated in either uncertainty management strategy. Therefore, analysis of these topics is not available in the present study.

Reported screening recommendations. Also included in the survey were assessments of participants' reported recommendations to female family members regarding breast cancer screening (mothers of male students were instructed to skip this section, and are excluded from the analysis). Participants were asked to provide the frequency with which they have recommended to the female family member participating in the study with them to have mammograms and clinical breast examinations and how frequently they have recommended breast self-examinations. Given that the categories provided are

[12] The Bonferroni method was used to adjust $\underline{P}$ in light of the potential for an inflated risk of making a Type I error with multiple comparisons; the $\underline{P}$ used to judge significance for this set of analyses is .013 (.05/4) for BSE and CBE and .01 (.05/5) for the mammogram.
[13] This finding was, of course, highly anticipated, but chi square analysis was conducted since a small number of female students reported having at least one mammogram.

based on screening recommendations and are not of equal intervals, conducting a comparison of means is not appropriate; thus, frequencies of responses and Pearson chi square analyses are reported to illustrate the findings. All 32 male students who participated in the survey indicated they had never recommended to their mothers to conduct breast self-examination, have a mammogram, or have a clinical breast examination. Therefore, the results reported in this section include only mothers of female students (N = 128) and female students (N = 128; combined N = 256). Table 13 provides a comparison of reported screening recommendations among mothers and daughters.

Table 13. Female Participants' Reported Screening Recommendations, N = 256

Type of Screening Recommended to Female Co-participant in Study	Mothers (n=128) f	Mothers (n=128) %	Daughters (n=128) f	Daughters (n=128) %	Total
Breast self-examination:*					
Monthly	36	28.1	17	13.3	53
Never	33	25.8	73	57.0	106
Some other frequency	38	29.7	11	8.6	49
Total Recommended BSE	107		101		208
Mammography:**					
Annually	5	3.9	20	15.6	25
Never	62	48.4	59	46.1	121
Some other frequency	45	35.2	23	18.0	68
Total Recommended Mammography	112		102		214
Clinical breast examination:*					
Annually	42	32.8	21	16.4	63
Never	40	31.3	68	53.1	108
Some other frequency	24	18.8	11	8.6	35
Total Recommended CBE	106		100		206

*Mothers reported significantly greater proportions; $p < .001$.
**Mothers reported significantly greater proportions; $p = .006$.

Mothers of female students reported recommending to their daughters to conduct breast self-examination monthly (36, or 28.1%) or never (33, or 25.8%) most often, followed by once a year or less (18, or 14.1%), a few times a year

(14, or 10.9%), weekly (5, or 3.9%), and daily (one response, or .8%). 73 female students, or 57%, reported they have never recommended breast self-examination to their mothers. Only 17, or 13.3%, of female students reported recommending to their mothers to conduct breast self-examination monthly, while six (4.7%) and 5 (3.9%) female students reported recommending to their mothers to conduct breast self-examination a few times a year and once a year or less, respectively.

Participants were also asked to report how often they recommend mammography to the female relatives participating in the survey with them. Most mothers -- 62, or 48.4% -- reported never having recommended a mammogram to their daughters, while 32 (25%) reported they have recommended to their daughters to have a mammogram whenever recommended by a physician. 5 mothers (3.9%) reported they have recommended their daughters have a mammogram once a year; the same number also reported recommending their daughters have a mammogram one time. Three mothers (2.3%) reported some other frequency. Fifty-nine daughters (46.1%) reported never recommending to their mothers to have a mammogram; 20 (15.6%) reported recommending once a year; 16 (12.5%) reported recommending according to physician's recommendations; 5 (3.9%) reported recommending once a year or less; one female student (.8%) reported recommending to her mother that she have a mammogram once every 2 years; and one female student reported she had recommended to her mother to have a mammogram at some other frequency.

Finally, in response to the question related to frequency of recommending clinical breast examination, 42 mothers (32.8%), reported recommending to their daughters to have a clinical breast examination once a year, while 40 mothers (31.3%) reported never recommending clinical breast examination to

their daughters. Seventeen mothers (13.3%) reported they had recommended their daughters have a clinical breast examination one time, while 7 (5.5%) provided some other recommendation. Over half (68, or 53.1%) of female students reported they have never recommended clinical breast examination to their mothers; 21 (16.4%) reported the recommendation of once a year; 9 students (7%) reported recommending that their mothers have a clinical breast examination one time; and 2 students (1.6%) reported a recommendation of once every two years. Analyses show significant group association with all three recommendations[14]: for recommending breast self-examination, Pearson $\underline{x}^2$ (5, $\underline{N}$ = 208) = 38.31, Cramer's $\underline{V}$ = .43, $\underline{p}$ < .001; for recommending mammography, Pearson $\underline{x}^2$ (5, $\underline{N}$ = 209) = 16.3, Cramer's $\underline{V}$ = .28, $\underline{p}$ = .006; and for recommending clinical breast examination, Pearson $\underline{x}^2$ (4, $\underline{N}$ = 207) = 23.85, Cramer's $\underline{V}$ = .34, $\underline{p}$ < .001.

Students' provision of breast cancer information. To explore the impact of efforts to include college students in activities designed to improve breast cancer awareness and knowledge described earlier, students were asked to indicate whether or not they had given breast cancer information to their mothers, and if so, what kinds of information they had provided. In sum, very few students reported that they had provided breast cancer information to their mothers. A total of 138, or 86.3%, of students reported they had never given breast cancer information to their mothers (including all 32 male participants). Specific topics of breast cancer information female students reported providing to their mothers and corresponding frequencies are provided in Table 14.

[14]The Bonferroni method was used to adjust P in light of the potential for an inflated risk of making a Type I error with multiple comparisons; the P used to judge significance for this set of analyses is .013 (.05/4) for BSE and CBE and .01 (.05/5) for the mammogram.

Table 14. Breast Cancer Information Provided to Mothers by Students, N = 160

Topic	f	%
Information on breast self-examination instruction (such as a shower card)	11	5.6
Information on screening guidelines	4	2.5
Information on how to obtain a mammogram	5	3.1
Information on genetic factors related to breast cancer	3	1.9
Information on fundraising events such as walks or races	6	3.8
Yes, cannot remember the specific type of information	3	1.9
Have never given printed information about breast cancer to the adult female relative participating in the study with me	138	86.3
Total	170[1]	

[1] Note: total number of responses is higher than N for student sample due to the ability of individual participants to indicate more than one category.

If student participants indicated they had given breast cancer information to their mothers, they were asked to identify the specific source(s) of the information. Campus organizations, the university health center, a newspaper or magazine article, and an organization such as the American Cancer Society were specifically indicated as sources of breast cancer information students had shared with their mothers. Three students indicated they could not remember the source of the breast cancer information they gave to their mothers. Frequency distributions for these sources of information are reported in Table 15.

Table 15. Sources of Breast Cancer Information Provided by Students to Mothers, N=160

Source	f	%
Campus organization	5	3.1
University health center	4	2.5
Newspaper or magazine article	8	5.0
Other organization, such as ACS	6	3.8
Cannot remember source of information	3	1.9
Total	26	

Reliability Measures of Items Included in the Study

The goal of the current study focused on providing information about the knowledge, behaviors, and beliefs among college students and their mothers regarding genetics and breast cancer, media and organizational messages about breast cancer, and family communication about breast cancer. Thus, the survey consisted largely of categorical variables designed to capture information related to specific topics and sources of breast cancer information. Developing new scales, or refining existing scales, was not a primary goal of the current study due to its exploratory nature. However, the four items designed to measure participants' knowledge about breast cancer risk and genetics, the three items measuring perceived accuracy of the information provided by the mass media, the two items measuring reported frequency with which participants recalled reading or hearing about breast cancer in the mass media, and three of the items in the family communication section (frequency of family communication

about breast cancer, comfort in discussing health, and perceived influence on health matters) were subjected to reliability analyses to provide additional statistical information about these survey items. The results of these analyses are presented in Table 16.

Table 16. Reliability Coefficients of Scales

Scale	# Items Included in Scale	Reliability Coefficient[1]
1. Breast cancer risk estimates	4	.267[2]
2. Mass media accuracy of breast cancer reports	3	.699
3. Mass media frequency of breast cancer reports	2	.654
4. Family communication about breast cancer & health	3	.346

[1] For Scale 1, K-R 20; For Scales 2-4, Cronbach's alpha.
[2]Only one item in this scale, participants' estimates of the percentage of breast cancers caused by a gene mutation, fully supported H1. When this item is deleted from the scale, the reliability coefficient improves to .307.

Not surprisingly, due to the exploratory nature of the study, reliability coefficients for the above scales are relatively low, particularly for the breast cancer risk estimates and family communication scales. Additional interpretation of these findings is provided in the Discussion.

CHAPTER 5

DISCUSSION

Summary and Interpretation of Results

Perceptions of Genetic Risk and Breast Cancer

The set of items related to participants' perceptions of genetic risk and breast cancer was designed to test the prediction that the majority of participants would overestimate genetic risk. This finding was only fully supported in one of the four individual items. Given that a number of previous studies have concluded participants generally overestimate genetic risk, the present findings merit further study to determine reasons for discrepancies in risk perceptions among specific populations.

Most participants in the current study provided inaccurate risk estimates. Group associations were not observed; students and mothers alike provided inaccurate estimates of genetic risk and breast cancer on average. Difficulty in understanding genetic risk estimates specifically, and the problems some individuals have in understanding numbers in general, or low numeracy, as cited by Woloshin et al. (2001), may contribute to participants' difficulty in providing accurate numeric estimates.

Breast Cancer Information in the Mass Media

Frequency reports and perceptions of accuracy. Mothers reported reading and hearing about breast cancer in the mass media significantly more than students and reported a significantly higher number of specific topics; female

students reported reading about breast cancer in these media significantly more than male students and also reported significantly more specific topics than the men. These findings are intuitive given the nature of the disease.

Mothers reported being fairly confident on average that the information they read in newspapers and magazines and hear on television is accurate; students' perceptions of accuracy of newspapers, magazines, and television were significantly higher than those of their mothers. Since the sample was derived from students attending an introductory public relations course in a college of journalism and mass communication, it makes sense that students would give high confidence ratings to the mass media. While data were not obtained related to the students' intended majors, by enrolling in such a course they demonstrated that they at least have an interest in public relations and would therefore to be more likely to have positive feelings toward the media in general.

Mass media topics. As indicated earlier, a number of researchers (Hallowell, Statham, & Murton, 1998; Henderson & Kitzinger, 1999; Richards et al., 1995; Sagi et al., 1998; Sutton, Balch, & Lefebure, 1995; Wonderlick & Fine, 1997) specifically point to media messages as creating confusion among women regarding knowledge and perceptions about genetic factors influencing the development of breast cancer. However, in the current study, topics related to breast cancer screening, breast cancer experiences of individual women, and environmental factors related to breast cancer were the categories most frequently reported by participants in general, regardless of age or sex. These

findings are in comparison with Henderson and Kintzinger's 1999 study examining media coverage of breast cancer, which found discussions about women considering prophylactic mastectomy and the experiences of women from "high risk families" (p. 565) as the most commonly reported topic area. In the current study, participants may have heard similar stories, but they reported remembering them, not as a story about the genetics aspect of breast cancer, but simply as stories about women's experiences with breast cancer in general. In addition, very few participants recalled ever hearing about any BRCA gene; this information would surely have been included in stories discussing genetics and breast cancer.

Based on these findings, assumptions that the mass media is responsible for creating inaccurate perceptions related to genetic risk for breast cancer may not be plausible, at least among the general public -- for even if further review shows stories included in the media during the time of the study did specifically include genetics information, this was not the primary information recalled by participants. Indeed, the belief that the mass media are responsible for creating misperceptions about genetics and breast cancer may even illustrate a third-person effect on the part of researchers, where "people judge the media to exert greater persuasive influence on other people than on themselves" (Paul, Salwen & Dupagne, 2000, p. 57).

As Perloff (2002) writes, the third-person effect hypothesis has two parts: (a) the perceptual hypothesis, which "asserts that people assume that

communications influence others more than the self," and (b) the behavioral component, which "suggests that people's expectations of media impact on others leads them to take action, perhaps because they want to thwart the predicted effects" (p. 490). This hypothesis has potential application to genetics counseling literature, where, for example, researchers are attempting to identify client motivations for extreme uncertainty management behaviors such as prophylactic mastectomy (i.e., Richards et al., 1995) and understand reasons for women's elevated perceptions of personal risk (i.e., Henderson & Kitzinger, 1999). While the current study is highly exploratory in nature and limited in scope related to the lack of diversity of participants, and thus by no means conclusive, its findings in this area suggest researchers should use caution in attempting to generalize findings of these previous studies to broader populations. Clearly, additional research among different groups is needed to develop more general knowledge about sources of influence on women's perceptions about genetics and breast cancer.

Family Communication about Breast Cancer

Frequency and nature of communication. Mothers and students alike reported discussing breast cancer with the family member participating in the study with them just over one or two times total on average; female students reported discussing breast cancer with their mothers significantly more often than males, and female participants in general also reported discussing breast cancer significantly more frequently than the male students on average.

Given that breast cancer is largely seen as a woman's disease, and also given the age of the male participants in the current study, it is understandable that these male participants would report discussing the topic less than their female counterparts. College-aged men may feel embarrassed or uncomfortable discussing this particular subject with their mothers or other family members. However, despite the differences in reported frequency of discussion, all participants reported discussing somewhere between two and three specific topics with their family members on average, and the groups did not differ significantly, either in total number or proportions, in the reported number of specific topics discussed.

The topics all participants reported discussing with family members most frequently were, in order: breast cancer screening, breast cancer of a friend, breast cancer of a family member, and genetic factors related to breast cancer. The latter finding supports previous research that has indicated families are important sources of information when dealing with genetic factors related to breast cancer (Clark et al., 2000; Green et al., 1997; Green & Thomas, 1997; Hallowell, 1999; Hallowell & Murton, 1998; Karp et al., 1999; Richards et al., 1995). Discussions of breast cancer of a friend or family member are also likely to include discussions about genetic risk, since these discussions are likely to include speculation related to the potential "causes" for the breast cancer of a friend or loved one and chances for others in the family to develop the disease.

Information about specific family members included in health communication. In addition to the family members participating in the study with them, participants provided other specific family members with whom they have discussed health. Mothers reported spouses, sisters, daughters, and sons most often; female students reported fathers, sisters, grandparents, and aunts or uncles most often; and male students reported fathers, grandparents, brothers, and sisters most often. Previous research (Green et al., 1997) has indicated female family relatives in particular are the most likely family members with whom women share information, questions, and concerns about breast cancer. The current research extends the possibility that both male and female relatives may be important sources of health information.

Other Sources of Breast Cancer Information

Specific sources and topics. Mothers reported significantly more sources and topics in this area than students; female students also reported significantly more sources and topics than males. Mothers most often identified their personal physician, friends, relatives, and other health professionals as other sources of breast cancer information; female students most often identified relatives, their personal physician, friends, physicians in general, and campus organizations; and male students most often identified relatives, friends, physicians in general and the Internet. These findings support and extend the results of previous research which specifically indicated physicians and family members are important sources of information about breast cancer (Clark et al., 2000; Wonderlick & Fine, 1997).

While the Internet was not among the most frequently reported sources by mothers, over one fourth of these women reported the Internet as an additional source of information, implying this may be another important resource in addition to interpersonal sources.

Campus organizations' role in the dissemination of breast cancer information to students. Campus organizations were of particular interest to the researcher as potential sources of breast cancer information among students. Students cited them in significantly higher proportions than mothers, almost a third of female students reported them as a source of breast cancer information, and female students cited them as breast cancer information sources significantly higher in proportion compared to males. Therefore, while not reported as often as interpersonal sources such as physicians, friends, and families, these organizations are potentially influential as a source of health information for college women.

Topics presented by these other sources. With regard to specific topics provided by these other sources of information, mothers and female students most frequently reported screening recommendations, issues related to screening practices, breast cancer of a person other than a celebrity, and environmental factors related to breast cancer. Male students most often cited breast cancer of a person other than a celebrity, breast cancer screening recommendations, and breast cancer of a celebrity. The consistency in topics reported from these sources and the mass media sources above indicates that

individuals may have difficulty in differentiating or remembering from which specific source they receive breast cancer information.

Uncertainty Management Strategies

The information-seeking and communication behaviors reported above can be considered uncertainty management strategies related to breast cancer. The following areas were included in the study as additional measures of uncertainty management behaviors among the current sample of college students and their mothers. In general, more mothers engaged in uncertainty management behaviors (communication, information-seeking, and screening) than students, and more female students than male students. These findings are intuitive given the nature of breast cancer; it makes sense that those at greater risk for developing the disease would seek out information from more sources, would report exposure to more specific types of information about breast cancer, would talk about breast cancer more frequently with family members and others, and would report higher percentages of reported screening behaviors than other groups.

Women's reported breast cancer screening behaviors. Female participants were asked to report the frequency with which they conduct breast self-examinations (BSE) and receive clinical breast examinations and mammograms. Analyses revealed that mothers reported each of these screening behaviors in significantly higher proportions than female students. Most mothers and students reported having annual clinical breast examinations, in accordance with

screening guidelines: all mothers reported having a clinical breast examination at least once, and most reported they have one a year; almost two-thirds of female students reported having annual clinical breast examinations, compared to just over one-fifth reporting they have never had one. For mammography, over three-fourths of mothers reported they have one mammogram per year, the frequency generally recommended for women in this age group. Less than 4% of mothers reported never having a mammogram. Strangely, 9 female students reported they have had at least one mammogram. Since no students participating in the current study are of the age where annual mammography is generally indicated, this finding merits further study; it is possible, for example, that these individual students misunderstood what a mammogram actually is, confusing it with some other procedure, in which case additional educational efforts would be helpful for these individuals. Another possibility is that these women are in "high risk" families, and even though they did not report participating in genetic testing or counseling for breast cancer, their physicians (or some other family health practitioner) may be recommending mammograms as an uncertainty management strategy. Finally, another possibility is that these student participants were simply not paying close attention when completing the survey and circled these items by mistake (a type of error inherent in any study involving surveys as a measurement tool).

Genetic testing and/or counseling. It was hoped that some participants would report participating in genetic testing and/or counseling for genetic risk

and breast cancer, since these behaviors are clearly uncertainty management strategies relative to identifying one's personal risk for developing the disease. Unfortunately, no participants indicated they had participated in either activity. Therefore, the current method of sampling appears inadequate to capture individuals who have participated in these activities; purposive sampling among those who report to such testing and counseling activities, currently employed by a number of studies in genetic counseling research, is probably the preferred method to recruit significant proportions of these individuals at the present time.

Recommending breast cancer screening to female family members. No male students reported giving a screening recommendation of any kind to their mothers. Most female students reported never recommending BSE, clinical breast examination, or mammography to their mothers. This is an area in need of further research; it appears that most mothers in this population are obtaining the recommended screenings for breast cancer, so it might be possible that these students are not recommending to their mothers to obtain screening because they know they already do so.

In comparison, the one screening behavior generally recommended for college-age women at the present time is breast self-examination. Just over 28% of mothers reported they had recommended to their daughters to conduct breast self-examination monthly, while just over one-fourth of mothers reported they have never recommended this screening method to their female students. And, while mammography is not indicated for college-aged women, less than half of

the mothers participating in the survey reported they have never recommended a mammogram to their daughters (the appropriate recommendation, based on current screening guidelines); more than half reported some other frequency. These findings illustrate potential confusion among mothers related to current screening recommendations for younger women.

Information Provision by College Students. No male students reported giving breast cancer information to their mothers, and few female students reported they have given information about breast cancer to their mothers. These findings show college students, while they are actively participating in awareness and fundraising efforts sponsored by health agencies, may not be interpreting these activities as education per se, but instead as a way to "get involved" on a more general level.

Reliability and Validity

Reliability. Reliability is defined generally as the accuracy or precision of a measuring instrument (Kerlinger, 1986). The current study was designed, for the most part, to collect categorical information regarding specific topics participants recalled hearing or reading about breast cancer, specific sources or individuals from whom participants recalled obtaining this information, and uncertainty management strategies. While statistical reliability is not calculated for categorical items, the current instrument proved reliable on a general level: participants were able to indicate a number of specific topics and sources related to breast cancer and provided specific information related to uncertainty

management strategies such as talking about breast cancer and participating in screening. In this sense, the current instrument provided a precise measure of specific categories of information reported by participants.

The study also included a handful of items designed to gather some preliminary information related to topics such as participants' estimates of breast cancer risk, perceptions of accuracy of breast cancer information, and frequency of communication about breast cancer. When interpreting statistical reliability related to these items, analyses showed low reliability, particularly for the breast cancer risk and family communication scales. The least reliable scale, statistically speaking, was the set of items designed to capture participants' perceptions and knowledge about genetics and breast cancer. These items provided a critical illustration of uncertainty and confusion related to participants' understanding of breast cancer risk estimates, and as such were highly beneficial relative to the goal of the current study. The low reliability of these items when interpreted together as a scale underscores the recommendation that researchers use caution in attempting to generalize individual findings related to perceptions about the role of genetics in the development of breast cancer. Clearly, these individual items are tapping separate subcategories within the overall domain of understanding breast cancer risk.

The reliability coefficient for the family communication scale was also quite low. As these items were not designed to "fit" together as a scale when the survey was developed, this finding is not surprising. These items are likely

indicative of separate but related subcategories within the overall domain of family communication about breast cancer and health. At .699 and .654, the media accuracy and frequency scales approached the .7 level, but these too need further refinement to be comfortably treated as a scale. Finally, the total number of items in each scale ranged from 2 to 4. Creating and adding new items designed to measure the same constructs will enhance statistical reliability in future studies attempting to design reliable scales to measure these constructs.

Validity. According to Kerlinger (1986), "the commonest definition of validity is epitomized by the question: 'Are we measuring what we think we are measuring'" (p. 417)? This question can be answered in several ways regarding the methods and results of the current study. Content validity, or the degree to which the items measured what they were designed to measure, was achieved by conducting extensive literature reviews, focus groups, and a pilot to assist in the development of the survey. An expert committee of communication scholars reviewed the survey prior to administration to further improve content validity.

The second type of validity, criterion validity, is typically demonstrated by comparing results of the current instrument to external variables (criteria) known to measure the same attributes (Kerlinger, 1986). The set of items designed to measure participants' knowledge about breast cancer risk were borrowed from a previous study (Wonderlick and Fine, 1997). This previous research found that participants generally provided estimates higher than the correct response to this

set of items, a finding only fully supported in one of 4 items in the present study. Thus, the criterion validity to this scale in particular is questionable in terms of its ability to accurately measure participants' knowledge about breast cancer.

However, the apparent confusion among participants related to their understanding of genetic and lifetime risk estimates and breast cancer actually demonstrates high construct validity (and construct validity is arguably "the most important form of validity from the scientific research point of view," Kerlinger, 1986), as these findings in particular appear to demonstrate a high level of uncertainty on the part of participants. Thus, the findings are in line with the theoretical framework on which the entire study was based.

Implications for Theory Development

Uncertainty management. Uncertainty management (Brashers, 2001) was the primary theoretical perspective employed to guide the current research. While the current study succeeded in identifying specific uncertainty management strategies among the groups studied, more research is now called for to identify the feelings or levels of uncertainty that are present related to these behaviors. Additionally, the present study did not attempt to measure the level of certainty participants felt regarding their estimates related to the breast cancer risk questions or their own perceived personal risk. To extend the application of uncertainty management theory to the study of perceptions of mothers and college students, additional research is needed to assess feelings of uncertainty related to individuals' perceived personal risk and understandings of

scientific information such as genetic risk for developing breast cancer as well as population-based risk estimates.

In measuring participants' reported confidence in the accuracy of the breast cancer information they recalled receiving from interpersonal, organizational, and mediated sources, the present study provided some preliminary indications of levels of certainty relative to the information provided by these sources. Additional research is now needed to further examine these perceptions.

Third person effects. As indicated earlier, the findings of the current study related to participants' overall perceptions regarding the role of genetics in the development of breast cancer were inconsistent. These findings somewhat contradict generalizations made in previous research that individuals tend to overestimate the role of genetics in the development of breast cancer, and the third person hypothesis was presented as a possible explanation for these perceptions. This theoretical perspective should also be considered in studies attempting to examine perceptions about genetics and breast cancer as a way to acknowledge that biases may exist on the part of health practitioners and researchers, who may wrongly assume that the media are responsible for public misperceptions about breast cancer, and in doing so may overlook other sources and types of information that may be causing or contributing to such misperceptions.

Narrative theory. Stories about women who are experiencing breast cancer was a specific topic commonly reported in the current study. This finding has implications for an additional area of theory development: the application of narrative theory to the study of public perceptions (and creation) of messages about breast cancer. As Gerbner et al. (2002) write, "television is a centralized system of storytelling. Its drama, commercials, news, and other programs bring a relatively coherent system of images and messages into every home. That system cultivates from infancy the predispositions and preferences that used to be acquired from other 'primary' sources that are so important in research on other media" (p. 44). This perspective, of mass media as storytelling, is central to Fisher's (1987) narrative paradigm.

According to Fisher (1987), the purpose of telling stories is to provide good reasons for others to believe or act in certain ways. Specifically, narratives are defined as attempts at storytelling that portray the interrelationships among behavioral recommendations and physical symptoms, and the psychological, social, and cultural contexts of these behaviors and symptoms (Waitzkin, Britt, & Williams, 1994). Narratives can be evaluated according to (a) "narrative probability," or the extent to which a story is coherent and free of inconsistencies and (b) "narrative fidelity," or the extent to which a story is consistent with listeners' or readers' personal experiences (Fisher, 1987). This paradigm could be used as a framework for future studies attempting to evaluate media stories about womens' personal experiences with breast cancer.

Implications for Future Research

Examination of Specific Media Messages Cited by Participants

Based on the findings of the current study, new studies should be conducted to examine the specific print media outlets cited by participants to determine the actual breast cancer information they contained around the time of the study. This information could shed light on some of the responses in the current study as well as provide useful information regarding mass media coverage of specific breast cancer issues.

Other Forms of Communication about Breast Cancer

Future studies should also examine other print forms of communication that may impact public perceptions and knowledge about breast cancer. For example, commercial texts that promote sponsorship of breast cancer-related activities were not specifically explored in the present study; these may also have an influence on women's perceptions, since commercial messages may include, or be accompanied by, education about breast cancer, such as screening recommendations and risk factors. Readers of these commercial texts may or may not consider them to be an important, credible source of health information, and may or may not be able to distinguish between these texts and actual news or feature articles in a newspaper or magazine.

Formal Evaluation of Education Targeted to College Students

Research should also be done to formally evaluate the efforts of organizations such as the American Cancer Society and Susan G. Komen

Foundation to specifically include college students in breast cancer education and awareness activities. Studies could evaluate not only existing materials (such as those included in Appendix A) and distribution methods, but identify additional messages that might enhance students' knowledge and perceptions about breast cancer and enable students to share that information with women such as their mothers and other older family members. In general, future studies should continue to identify the kinds of health information shared among mothers and their college-age children and examine the potential for improving and reinforcing health communication in this population.

Audiences to Include in Future Studies

The current study was highly limited in scope regarding the participants; most were Caucasian and female, and coming from relatively affluent and highly educated households. These variables may influence perceptions, knowledge, and screening behaviors (the latter is believed to be likely in particular, since women with lower household incomes are not as likely to be able to afford annual clinical examinations and mammography). Future studies might recruit mother and student participants from high schools, technical colleges or junior colleges, and minority colleges to gain more diversity in sampling of students and mothers. Additionally, as the current study was limited to one university in the southeastern United States, similar studies should be conducted in varying geographical areas to further improve diversity of participants.

Methodological Recommendations

New scales should be developed to further examine specific constructs and topics included in the current research. For example, the questions designed to capture participants' breast cancer risk estimates need to be reworked to capture not only participants' estimates, but their reasoning behind these estimates and level of certainty regarding the correctness of risk estimates. Given the inconsistency in responses of these items, such information could provide insight into the causes for such inconsistencies and illustrate specific opportunities for health education. Numeracy issues with regard to providing numeric estimates of risk should also be explored further. Such studies could shed light on findings that research participants often tend to overestimate, or inaccurately estimate, genetic risk related to a number of topics, including breast cancer.

The items designed to capture mass media messages about breast cancer, while helpful in providing direction regarding specific media outlets and topics participants recall the most, should now be expanded to gather more detailed feedback about information obtained from specific media outlets. The family communication items could also be expanded to attempt to gather specific information relative to each individual family member. In general, developing and refining additional semantic differential-type items and scales with equally occurring intervals would enable researchers to conduct additional statistical analyses beyond the scope of the current instrument. Advanced categorical

statistics, such as log-linear modeling (see Denham, 2002), could be applied to the existing instrument to further examine possible statistical associations and relationships among variables.

Future research might also employ exploratory, qualitative methods in attempting to gain insight from young men about their uncertainty management strategies related to perceptions about breast cancer. For example, a male student whose mother or other close relative has been diagnosed with breast cancer may employ focused information-seeking strategies at that time to attempt to learn more about his family member's disease. Therefore, while men did not report these information-seeking behaviors in frequencies as high as the females in the present study, the finding that they did report reading, seeing, or hearing about specific breast cancer topics from a variety of sources may actually constitute a very high level of uncertainty management among this group of men. Conversely, they may have simply overheard conversations, news reports, or stories being discussed by friends or family members. Qualitative methods such as focus groups or interviews could draw out the reasons and motivations behind the reports provided here.

Implications for Practice

Specific Media Outlets to Include in Health Communication Efforts

Participants in the current study identified several specific media outlets, including national and local sources, from which they remember obtaining information about breast cancer, indicating these specific outlets are potentially

important sources of information about breast cancer. Practitioners could consider focusing on these specific media outlets (i.e., local news, national news, and women's magazines) when planning distribution of breast cancer information.

Opportunities for Health Communication Efforts Targeting Families

Mothers in the current study perceived themselves as significantly more influential as a source of health information than students, and, on average, participants in general reported somewhat to strongly agreeing to the statement that they feel comfortable discussing health matters in general with the person participating in the study with them. These findings indicate the potential to target mothers specifically with recommendations about specific messages to provide to their children. For example, the one screening behavior generally recommended for college-age women is breast self-examination. Just over 28 % of mothers reported they had recommended to their daughters to conduct breast self-examination monthly, while just over one-fourth of mothers reported they have never recommended this screening method to their female students. Future communication efforts could be aimed specifically at encouraging mothers to recommend BSE to their daughters (unless evidence continues to support findings of Thomas et al.'s 2002 study, where researchers found BSE did not reduce mortality rates; if this is the case, one would hope screening guidelines and the corresponding recommendations to women would be adjusted to reflect medical data).

Additionally, the finding that none of the male participants had recommended screening to their mothers or provided them with information about breast cancer even though they indicated they feel comfortable discussing health with their mothers highlights an opportunity for education and awareness efforts targeting young men, who could be given specific information related to screening guidelines and resources, with recommendations to share that information with their mothers.

Opportunities for College and University Health Campaigns

As indicated previously, very few college students participating in the current study indicated they have given breast cancer information to their mothers. Given recent efforts by national and local cancer organizations to provide information about breast cancer to college students and involve them in activism and fundraising efforts, these findings illustrate an opportunity for health agencies to provide some specific recommendations to the students they are targeting with education and awareness efforts. Students could be specifically encouraged to share the information they obtain with their mothers and other adult female relatives, who are likely within the age where annual mammography is recommended. For example, organizations funding distribution of educational shower cards, such as those included in Appendix A, could specifically recommend that female students take two cards, keeping one for themselves and giving one to their mothers.

Strengths of the Current Study

Surveying college students and their mothers proved a useful method for assessing family communication about breast cancer, the impact of education and awareness efforts directed specifically at college students, important sources of breast cancer information and specific topics, and uncertainty management strategies related to breast cancer risk. The findings of the current study provide important new information related to the types of health communication currently being accessed and recalled by these groups. For example, in many areas of reported mass media exposure and family communication, individual topics were reported in strikingly similar proportions by students and their mothers, showing that students and their mothers may have common concerns, questions, and interests related to breast cancer.

The responses of the male students show it is important to include this group in studies about breast cancer; male students were able to report hearing or reading about specific breast cancer topics in the mass media, and reported specific sources of information. Finally, a number of uncertainty management strategies were illustrated in participants' responses. In general, more mothers engaged in uncertainty management behaviors (communication, information-seeking, and screening) than students, and more female students than male students. These findings are intuitive given the nature of breast cancer; it makes sense that those at greater risk for developing the disease would seek out information from more sources, would report exposure to more specific types of

information about breast cancer, would talk about breast cancer more frequently with family members and others, and would report higher percentages of reported screening behaviors than other groups. However, the current study provides solid (albeit preliminary) quantitative evidence of the specific types, frequency, and sources of breast cancer information among these groups.

Limitations

Attempts should not be made to generalize the present findings to external populations, given the nature of the sampling method employed and limited scope of participants. Participants were mostly Caucasian and female, with high education and income levels. However, the findings are useful in terms of providing new information related to the knowledge, perceptions, and reported behaviors of college students and their mothers in this specific geographical setting.

Furthermore, the current study, while adopting an uncertainty management framework, did not specifically assess participants' perceived uncertainty regarding the risk estimates they provided related to genetics and breast cancer. And, while the current study was somewhat innovative in specific efforts to include male college students, a population largely ignored in prior attempts to learn about perceptions related to breast cancer, the population of male participants in the current study was relatively small. Researchers interested in including males as participants in studies about breast cancer should make additional efforts to secure their participation.

The current study also did not ask participants to provide estimates of frequency of media use in general. The finding that mothers reported hearing or reading about breast cancer more frequently in the mass media than students might simply be an artifact of overall increased media consumption among mothers compared to college students. In contrast, if mothers had reported they watch television and read newspapers and magazines less frequently than students in general, but still reported reading or hearing about breast cancer in significantly higher proportions, these significantly higher proportions could then be more directly attributed to other factors, such as a higher level of involvement on the topic. Future studies should include such measures to provide a context for results related to specific topics.

Finally, the current study did not directly examine the specific media outlets from which participants indicated they have obtained breast cancer information. Future research should continue to directly examine media messages about breast cancer, and genetics specifically, to identify the specific information being provided by these sources in attempts to better understand public perceptions about genetics and breast cancer.

Conclusions

Some general conclusions can be drawn on the current research based on the findings presented above. With regard to perceptions about the role of genetics in the development of breast cancer, participants gave conflicting evaluations related to perceptions of genetic risk and breast cancer; these

findings merit further study and caution should be exercised by those attempting to make generalizations that individuals tend to overestimate the role of genetics in the development of breast cancer. These data also support the recommendations of researchers such as Champion and Springston (1999), who specifically suggest tailoring individual messages to specific audiences to account for differences in perceptions, knowledge, and motivations related to breast cancer education and screening.

In the present study, genetics did not appear among the topics participants remembered hearing or reading about most often in the mass media. However, mothers did report hearing or reading about some specific genetics topics in significantly greater proportions than their sons and daughters. Others, such as physicians, friends, and relatives, were verified as important sources of health information, and these sources were reported as providing information similar to the types obtained from the mass media. Thus, it is not appropriate to assume that one particular source (i.e., the mass media) is more responsible for creating public misperceptions than another, based on the current study's findings. In contrast, breast cancer of a friend or family member and genetic factors related to breast cancer were among the most frequently reported topics of family communication about breast cancer. Thus, future research might instead focus on family communication as a potential source of information, or misinformation, about the role of genetics in the development of breast cancer.

REFERENCES

Andrykowski, M.A., Munn, R.K. & Studts, J.L. (1996). Interest of learning of personal genetic risk for cancer: A general population survey. Preventive Medicine, 25(5), 527-536.

Armstrong, D. (1995). The rise of surveillance medicine. Sociology of Health and Illness, 17, 390-398.

Babrow, A.S., Hines, S.C. and Kasch, C.R. (2000). Managing uncertainty in illness explanation: An application of problematic integration theory. In B. Whaley (Ed.,) Explaining illness: Research and strategies (pp. 41-67). Hillsdale, NJ: Erlbaum.

Babrow, A.S., Kasch, C.R., and Ford, L.A. (1998). The many meanings of uncertainty in illness: Toward a systematic accounting. Health Communication, 10, 1-23.

Baty, B.J., Venne, V.L., McDonald, J., Croyle, R.T., Halls, C., Nash, J.E., & Botkin, J.R. (1997). BRCA1 testing: Genetic counseling protocol development and counseling issues. Journal of Genetic Counseling, 6(2), 223-244.

Brashers, D.E. (2001). Communication and uncertainty management. Journal of Communication, 51(3), 477-497.

Cartwright, L. (1998). Community and the public body in breast cancer media activism. Cultural Studies, 12(2), 117-138.

Champion, V.L. & Springston, J. (1999). Mammography adherence and beliefs in a sample of low-income African American women. International Journal of Behavioral Medicine, 6(3), 228-240.

Clark, S., Bluman, L.G., Borstelmann, N., Regan, K., Winer, E.P., Rimer, B. & Skinner, C.S. (2000). Patient motivation, satisfaction, and coping in genetic counseling and testing for BRCA1 and BRCA2. Journal of Genetic Counseling, 9(3), 219-235.

Claus, E.B., Risch, N.J. and Thompson, W.D. (1991). Genetic analysis of breast cancer in the Cancer and Steroid Hormone Study. American Journal of Human Genetics, 48, 232-242.

Condit, C. (2001). What is 'public opinion' about genetics? Genetics, 2, 811-815.

Condit, C.M. (1999). The meanings of the gene. Madison, WI: University of Wisconsin Press.

Denham, B.E. (2002). Advanced categorical statistics: Issues and applications in communication research. Journal of Communication, 52(1), 162-176.

Evans, D.G.R., Blair, V., Greenhalgh, R., Hopwood, R., and Howell, A. (1994). The impact of genetic counseling on risk perception in women with a family history of breast cancer. British Journal of Cancer, 70, 934-938.

Fisher, W. (1987). Human communication as narration: Toward a philosophy of reason, value, and action. Columbia: University of South Carolina Press.

Gagnon, P., Massie, M.J., Kash, K.M., Gronert, M., Heerdt, A., Brown, K., Sullivan, M., and Borgen, P. (1996). Perception of breast cancer risk and

psychological distress in women attending a surveillance program. Psycho-Oncology, 5, 259-269.

Green, J., Richards, M., Murton, F., Statham, H. & Hallowell, N. (1997). Family communication and genetic counseling: The case of hereditary breast cancer. Journal of Genetic Counseling, 6(1), 45-61.

Green, R.M. & Thomas, A.M. (1997). Whose gene is it? A case discussion about familial conflict over genetic testing for breast cancer. Journal of Genetic Counseling, 6(2), 245-255.

Green, S.B., Salkind, N.J. & Akey, T.M. (1999). Using SPSS for Windows: Analyzing and understanding data. Upper Saddle River, NJ: Prentice Hall.

Hall, J.M., Lee, M.K., Newman, B., Morrow, J.E., Anderson, L.A., Huey, B., & King, M.C. (1990). Linkage of early-onset familial breast cancer to chromosome 17q21. Science, 250, 250-1684-1689.

Hallowell, N. (1999). Doing the right thing: Genetic risk and responsibility. Sociology of Health and Illness, 21(5), 597-621.

Hallowell, N. & Murton, F. (1998). The value of written summaries of genetic consultations. Patient Education & Counseling, 35(1), 27-34.

Hallowell, N., Statham, H. & Murton, F. (1998). Women's understanding of their risk of developing breast/ovarian cancer before and after genetic counseling. Journal of Genetic Counseling, 7(4), 345-364.

Hallowell, N., Statham, H., Murton, F., Green, J. & Richards, M. (1997). 'Talking about chance': The presentation of risk information during genetic

counseling for breast and ovarian cancer. Journal of Genetic Counseling, 6(3), 269-286.

Hansen, M., Ed. (2002, Spring). RE/MAX joins ZTA in recognizing breast cancer survivors. Themis of Zeta Tau Alpha, 100(3), 25.

Henderson, L. & Kitzinger, J. (1999). The human drama of genetics: 'hard' and 'soft' media representations of inherited breast cancer. Sociology of Health and Illness, 21(5), 560-578.

Kahl, M.L. & Lawrence-Bauer, J. (1996). An analysis of discourse promoting mammography. In R. Parrott and C. Condit, Eds., Evaluating Women's Health Messages: A Resource Book, pp. 307-322. Thousand Oaks, CA: Sage.

Karp, J., Brown, K.L., Sullivan, M.D. & Massie, M.J. (1999). The prophylactic mastectomy dilemma: A support group for women at high genetic risk for breast cancer. Journal of Genetic Counseling, 8(3), 163-173.

Kash, K., Holland, J.C., Halper, M.S. & Miller, D.G. (1992). Psychological distress and surveillance behaviours of women with a family history of breast cancer. Journal of the National Cancer Institute, 84, 24-30.

Kerlinger, F.N. (1986). Foundations of Behavioral Research, 3rd Ed. New York: Harcourt Brace Jovanovich.

Kline, K.N. (1999). Reading and reforming breast self-examination discourse: Claiming missed opportunities for empowerment. Journal of Health Communication, 4(2), 119-141.

Lane, D.S., Polednak, A.P., Burg, M.A. (1989). The impact of media coverage of Nancy Reagan's experience on breast cancer screening. American Journal of Public Health, 79, 1551-1552.

Lerman, C., Lustbader, E., Rimer, B., Daly, M., Miller, S., Sands, C. and Balshem, A. (1995). Effects of individualized breast cancer risk counseling: A randomized trial. Journal of the National Cancer Institute, 87, 287-292.

Lerman, C. and Schwartz, M. (1993). Adherence and psychological adjustment among women at high risk for breast cancer. Breast Cancer Research and Treatment, 28, 145-155.

Lerman, C., Trock, B., Rimer, B., Jepson, C., Brody, D., and Boyce, A. (1991). Psychological side effects of breast cancer screening. Health Psychology, 10, 259-267.

Lloyd, S., Watson, M., Waites, B., Meyer, L., Eeles, R., Ebbs, S. and Tylee, A. (1996). Familial breast cancer: A controlled study of risk perception, psychological morbidity and health beliefs in women attending for genetic counseling. British Journal of Cancer, 74, 482-487.

Newman, B., Austin, M.A., Lee, M. and King, M-C. (1988). Inheritance of human breast cancer: Evidence for autosomal dominant transmission in high risk families. Proceedings of the National Academy of Science, USA, 85, 3044-3048.

Parsons, E. and Atkinson, P. (1992). Lay constructions of genetic risk. Sociology of Health and Illness, 14, 437-455.

Paul, B., Salwen, M. & Dupagne, M. (2000). The third-person effect: A meta-analysis of the perceptual hypothesis. Mass Communication and Society, 3(1), 57-85.

Richards, M.P., Hallowell, N., Green, J.M., Murton, F. & Statham, H. (1995). Counseling families with hereditary breast and ovarian cancer: A psychosocial perspective. Journal of Genetic Counseling, 4(3), 219-233.

Sagi, M., Kaduri, L., Zlotogora, J. & Peretz, T. (1998). The effect of genetic counseling on knowledge and perceptions regarding risks for breast cancer. Journal of Genetic Counseling, 7(5), 417-434.

Sheedy, K. (2000). Transcending tragedy: A 'comic' critique of public discourse about breast cancer genetics, 1987-1997. Unpublished doctoral dissertation.

Sutton, S.M., Balch, G.I., & Lefebure, R.C. (1995). Strategic questions for consumer-based health communications. Public Health Reports, 110(6), 725-736.

Thomas, D.B., Gao, D.L., Ray, R.M., Wang, W.W., Allison, C.J., Chen, L., Porter, P., Hu, Y.W., Zhao, G.L., Pan, L.D., Li, W., Wu, C., Coriaty, Z., Evans, I., Lin., M.G., Stalsberg, H. & Self, S.G. (2002). Randomized trial of breast self-examination in Shanghai: Final results. Journal of the National Cancer Institute, 94(19), 1445-1457.

Waitzkin, H., Britt, T., & Williams, C. (1994). Narratives of aging and social problems in medical encounters with older persons. Journal of Health and Social Behavior, 35(12), 322-248.

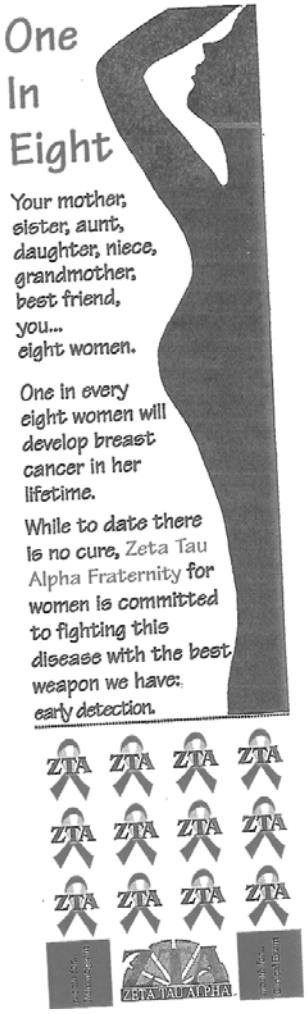
Wardle, J. (1995). Women at risk of ovarian cancer. Journal of the National Cancer Institute Monographs, 17, 81-85.

Woloshin, S., Schwartz, L.M., Moncur, M., Gabriel, S., & Tosteston, A.N. (2001). Assessing values for health: Numeracy matters. Medical Decision Making, 21(5), 382-90.

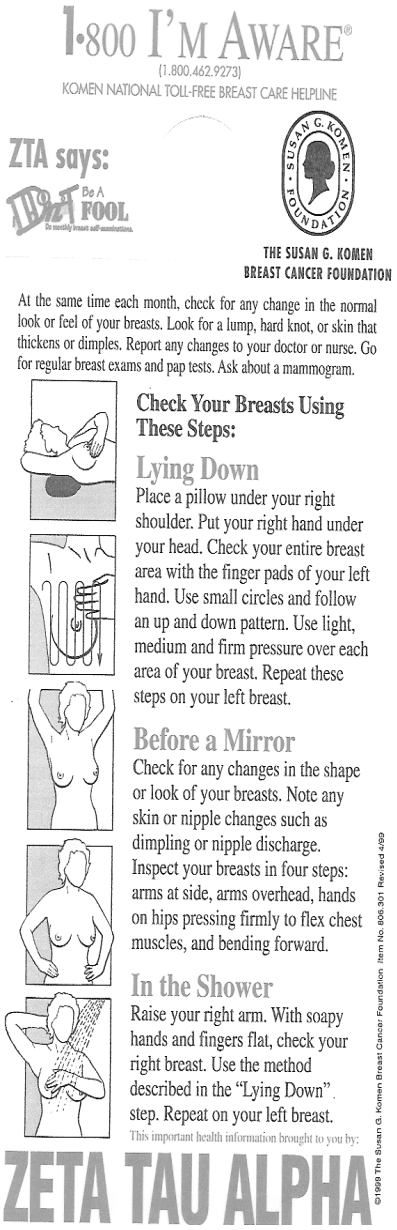
Wonderlick, A.L. & Fine, B.A. (1997). Knowledge of breast cancer genetics among breast cancer patients and first-degree relatives of affected individuals. Journal of Genetic Counseling, 6(2), 111-130.

APPENDICES

Appendix A: College Awareness Materials



BSE Calendar Reminder Stickers



BSE Shower Card

Appendix B: Focus Group Moderator Guide and Transcripts

Moderator's Guide
Breast Cancer and Genetics
July 2002

INTRODUCTION

Hello. I would like to welcome you all here today for our focus group discussion. My name is _____ and I will be moderating our discussion today.

The primary purpose of the focus group you are participating in today is to assist in the development of a survey that will be given to UGA students and their mothers on genetics and breast cancer. Today, we will be talking about the influence of family history on the development of breast cancer, sources of health information, family communication, and ways to administer surveys. Your suggestions, perceptions, and ideas will be used to help develop survey items, topics, methods and incentives.

We want to hear all about your perceptions, concerns, and attitudes about genetics and breast cancer, as well as suggestions for facilitating the completion of the survey. We would like your comments to be frank and honest; there are no right answers. We are looking for your thoughts and insights. You are the experts and we want to learn from you.

GUIDELINES

Here are a few guidelines. This is a relaxed and informal discussion.

This session is being taped, so please allow one person to speak at a time. Your comments are entirely confidential. The discussion should last about an hour or so. You are being provided with (lunch/dinner/snacks) as a thank you for your participation and valuable time. Please feel free to help yourselves to more food or drinks at any time. Are there any questions at this point? If not, let's get started.

Let's begin by going around the room and introducing ourselves. Tell us your name, home town, year in school, and anything else you would like others to know about yourself. To get things started, I'll tell you a little bit about myself…

DISCUSSION

Part 1. The Role of Genetics in the Development of Breast Cancer

1.a. My first question for you is a pretty broad one: How important of an influence is genetics in determining whether or not a woman will get breast cancer? In other words, in general, how much does a woman's family history affect her personal risk of getting the disease?

PROBE: Do you think there is a certain percentage or number of breast cancers that are caused by genetics? What percentage of breast cancers would you say are caused primarily by genetic factors?

1.b. How do you think genetics compares to other factors, for example, the environment or personal behaviors, in influencing the development of breast cancer? (examples of personal behaviors: diet, exercise, getting regular mammograms/clinical exams, self breast exam)

Part 2. Mass Media and Internet Sources for Health, Genetics and Breast Cancer

2.a. Next we are going to talk briefly about information you may have heard or read in mass media sources such as television and newspapers. First, in general, do you remember hearing/reading health information in the mass media? What kinds of information have you heard or read?

2. b. Do you remember hearing or reading about breast cancer specifically in the mass media? If so, what kinds of things have you heard or read?

PROBE, if needed: Screening guidelines? BRCA/other genetics stories? Treatment methods?

2.b. If you remember hearing about breast cancer in the media, do you remember specific sources, such as specific news programs, entertainment/talk shows, newspapers?

2.c. How trustworthy do you think this information was? In other words, did you believe the information you heard about breast cancer from these specific sources? Why or why not? Which ones did you think were the most credible or believable? Why?

2. d. Do you remember reading about health on the internet? If so, do you remember which specific sources (i.e., hospital sites, CDC or other govt sites,

specific commercial sites)

2. e. Do you remember reading anything about breast cancer specifically on the internet? If so, what did you read? Did you think this information was credible? Why or why not?

Part 3:Family Communication About Health, Genetics and Breast Cancer

3. a. The next subject we are interested in is how much you talk about health issues with family members. So, to begin, would you say you discuss health matters in general with your family members a great deal, once in a while, or never?

3. b. What kinds of topics do you discuss? Are there specific topics you discuss more than others? Which ones?

3. c. Which specific family members do you talk with the most about health issues?

4. d. Have you ever discussed breast cancer with a family member? If so, which family member(s)? How frequently have you discussed breast cancer with this person(s)?

4. e. Have you ever specifically discussed genetics and breast cancer with a family member? What did you discuss? (For example, immediate family history, family history of a friend/acquaintance, statistics on genetics and breast cancer) How frequently have you had these discussions?

4. f. If you have NEVER talked about breast cancer and genetics with a family member, why not?

Part 4: Suggestions for Survey Methods and Incentives

4. a. Now for the last part -- we're almost done. As I mentioned at the beginning of our discussion, your responses will be used to help develop a survey for college students and their mothers about breast cancer and genetics. We are considering a few different ways of conducting the survey, so we want to get your ideas about what you think would work the best. First, we are considering offering a web-based version of the survey in addition to paper and pencil format. Do you think offering these alternatives would be helpful? Why or why not?

4. b. How many of your moms have access to the internet?

4. c. Do you think your moms would be likely to use the web-based survey or would they prefer to fill out and return a paper-and-pencil version?

4. d. We are going to offer course credit to students who complete the survey. What do you think would help facilitate getting moms to complete the survey as well? In other words, should we offer course credit to students only if their parents also complete the survey? Is there another incentive that would be more effective in getting both the moms and their daughters to complete the survey?

5. e. We are also trying to decide how to involve the male students. We have considered having them fill out a different version of the survey, or getting them to recruit another female student and her mother to complete the survey. As a student, what do you think would be a fair way to involve the male students?

Before we wrap up, are there any other questions or suggestions you have that have not been addressed?

CONCLUSION

We want to thank each of you for participating in our group discussion this evening. The information you have given us will be extremely helpful in our research. Thank you.

Mothers Focus Group
Sept. 15, 2002

M: Okay, I guess we have to get some work done. The primary purpose of this focus group as y'all know is to help me develop my survey that I'm going to give to Grady College students and their moms later this semester. So today, just to refresh your memory, we're going to be talking about the influence of family history on the development of breast cancer, sources of health information, family communication, and ways to administer surveys. And, your suggestions, perceptions, and ideas will be used to help develop survey items, topics, methods and possible incentives. I want to hear all about your perceptions, concerns, and attitudes about genetics and breast cancer as well as suggestions for facilitating the completion of the survey. I want for your comments to be frank and honest; there are no right answers. I am looking for your thoughts and insights. You are the experts and I want to learn from you. Here are my guidelines: this is very relaxed and informal discussion. If you need to get up to use the restroom, or if you would like to get some more food or tea, please feel free. Since I'm taping, since I have to transcribe, please let one person speak at a time. The food is my thanks to you for participating.

Do y'all have any questions for me at this time? No? Ok. Well, my guide says for us to introduce ourselves at this point but since we all know each other I don't think we need to do that. (Laughter)

Ok. So my first question for you is a pretty broad one. How important of an influence is genetics in determining whether or not a woman will get breast cancer? In other words, in general, how much do you think a woman's family history affects her personal risk of developing breast cancer? And I know this is a very home-hitting topic for you (directed at one participant whose mother underwent a mastectomy for breast cancer the previous week), so ...

P1: I think tremendously, and I think a lot of women aren't aware of that. Of course, with mother now having it, mother's first cousin, and this is all maternal side ... And that's something else I don't think women realize, and that I have just found out, I always used to be scared to death because my father's side of the family, his mother, his mother's mother, and his mother's three sisters all died of various cancers of one form or another. One was melanoma, one was breast, one was just eat up -- it was cancer, but it was every form of cancer you can think of. One was ovarian, one was breast, one was all organs, one was melanoma, and the other one I don't even remember. But I used to be afraid to death, when used to go, I went to the dermatologist the week after I buried my paternal grandmother to have every mole from stem to sternum checked and removed if it was even remotely suspicious. There are certain moles that are more prone to growing into a melanoma cancer than others. I had them all removed, stopped going out in the sun for risk of sun cancer, I just don't do it, or if I do, I'm protected. I'm sunscreened, I've got a hat, but mostly I just stay out of it. Um, have regular mammograms and Pap smears. But always feared on my father's side of the family because of all the female members. Then I had, my general physician told me that women don't need to look so deeply into their paternal side of their family and cancer as they do their maternal. That it mostly comes from the female, from

mother to mother. That it's your female side of the family that you need to be more concerned if they have a history of cancer than it is your father's side. And I never knew that. And then after mother developed this cancer and then, first cousin had died of it nine years ago, um, it seems to kind of run true. So I think women would be very wise to investigate the maternal end of their families.

M: Did he give you any idea of how that affected you personally in terms of your personal risk? Has anybody ever said to you, since this person and this person and this person in your family has it, your personal risk is this much higher?

P1: Nobody's ever given me any kind of percentage or anything. They just always, um, what mother's surgeon said to me was if you are not already doing so you need to have regular mammograms. Well, I've been doing that for seven years. And it's not the most, it isn't fun (laughter) ...

P2: That's an understatement.

P1: I mean, it really and truly is an understatement. But that rates right up there with regular Pap smears. Not the greatest thing in the world to do, but for your own well being, early detection is three fourths of beating anything.

M: So, --, I take it you have mammograms too because you ...

P2: I do have mammograms. I have one yearly now. I'm only 45, but I had a hysterectomy a few years ago and I do take progesterone -- I'm sorry, ...

P1: Primarin.

P2: Primarin, every day. Thank you.

P1: I know because we take the same thing.

P2: So if I run out I just go to her office. (laughter) So even though it's not a very high dose, he feels that, my surgeon, that just given my age, getting into this age group, that I should have yearly mammograms. So I started last year getting a yearly mammogram. I'd had them before, but that was four or five years ago.

M: --, I know you're too young to get mammograms (participant is 37) ...

P3: Yeah, I've started.

M: But you're 37, right?
P3: Yeah. I just started this year.

M: Oh, did you. Was that because your doctor said you should start, or you just felt like you wanted to start doing it early?

P3: I just kinda wanted to start doing it early.

M: Wow, so y'all are really ...

P2: But nobody in my family has had breast cancer. My grandmother had ovarian or cervical cancer, I can't remember which, but she died from it, but ...

M: So it wasn't because of any family history ...

P2: It's because I take the hormones.

M: Well, just in general, do y'all agree with -- that you think family history is really influential?

P2: Absolutely, no doubt.

M: If you had to put a number on it, what would you say? Like, in terms of, if you had to put a number on how much a family history of breast cancer increases a woman's risk, what would you guess just as a ...

P2: I would think that just the chance itself would be at least probably 90 percent.

P1: I would too.

P2: Not that it would necessarily develop into cancer or that the daughter might, you know, like in --'s case, that she would necessarily develop breast cancer, or any type of tumors or anything, but I just think that the risk is so high genetically, if you have a genetic link to somebody who has had it.

P1: That holds true I think for a lot of things.

P2: Absolutely.

P1: Not just cancer. High blood pressure, diabetes ...

P2: Obesity...

P1: Obesity, all of these things tend to run in families, and people don't realize, especially in this day and age people don't realize especially in this day and age when you've got so many distant, single parent families where the mothers are raising kids and they're out, you know, you need to be careful who you're out there messing with, truly, your kids can develop all kinds of things, and if you can't really trace back both sides of your family's medical history, so that you're kind of at least aware of what's out there ...

M: Yeah, now that I have a child, I think about that a lot more, but when you're dating, you don't even think about that kind of stuff -- it's not even in the thought process.

P1: But there is very, very strong evidence that these things ring true.

P2: I have a brother-in-law who has Down's Syndrome. What they used to call Mongoloid. This is my husband's brother that I'm talking about. But, my mother-in-law had two children that died right after birth, and they did not know it until years later but those two children were Down's. There were two girls that were Down's. And, my mother in law has a niece, her sister's daughter, that has a child with Down's. So they had told us when I was pregnant with my first child of course I was really kind of apprehensive, you know, even though if I had a child that had Down's Syndrome or was retarded in some way, I would love them just the same. But I did have a doctor tell me that, you know, this runs in your husband's family and by law I need to tell you what your options are. That was pregnant with my second child, when he told me that. When I was pregnant with Heather, of course, I would not have aborted her. But at any rate, it seems to be, he even did a case study, he was doing his own little research, and he spoke with my mother-in-law, and he spoke with my husband of course, and he also spoke with my husband's aunt who has the daughter that has the child. So, it was somewhere in the family, maternal line, it was, I don't know, the gene or the DNA or something that was somehow pretty powerful.

M: How do you think genetics compares to other things like the environment or personal behaviors, like you said, prevention. How do you think it compares to those kinds of things in influencing the development of breast cancer?

P2: I think personally there is a lot of influence from breathing fumes, from cars, you know ...

M: So, environmental factors ...

P2: Yeah, you know, you eat foods with different types of preservatives on them. I think it does have an effect on your body. The other day I was amazed, I was listening to Good Morning America, and they had a segment on there where you can buy soap that has caffeine in it. And you rub it on your body. So they actually had someone on there doing it, a guy was showering with it, and he comes out and said, "I can tell." Apparently it had enough caffeine as 12 ounces, or 20 ounces, whatever is in a cup of coffee, that's the effect it has. So, I'm sitting there thinking, if that is absorbed in your skin, what else do we have? I mean, I have acrylic nails put on me, I wonder what is being absorbed in my nail beds, in my blood stream, I don't know.

M: What do y'all think about exercise, or things like that that you hear, you know, diet. How do you think that compares in terms of its influence on whether or not you are going to develop a disease?

P1: You can be the fittest person in the world and I don't think it'll stop cancer if it decides to affect your life. I think being in better physical shape can help you fight it, but if a cancer is gonna grow in you, it's gonna grow in you regardless of how well you exercise. Diet may contribute to some extent, I think people who eat healthier and try not to put all the additives and preservatives in their bodies are probably less likely to develop cancer than others, but I've never seen anything or read anything that directly correlates.

P2: The only think I can think of is that exercise can help keep off weight. And if obesity is a contributing factor to breast cancer in some women, it may not be, but if they say that obesity is, that might help maybe, you know, to stave it off, or ...

M: So kind of indirectly, it might have an influence?

P2: Because I do know that exercise is very good for other things, high blood pressure, mental stability, cardiovascular, sugar levels if you are a diabetic, so I would think that it would have some sort of an effect, but I'm not sure.

P1: I worked in oncology at Athens Regional for a long time as a unit secretary. I've seen tall, skinny, fat, short -- it doesn't have those -- not all fat, short women are gonna get breast cancer. It doesn't just pick on you. It, it ...

M: It's not selective.

P1: Nope. It doesn't care. It doesn't care what color you are, it doesn't care what height you are.

P2: That makes me think all the more then that genetics are even a bigger part of, you know, ...

P1: Well look at, there are certain disorders that only strike certain people. Take sickle cell, for instance, is strictly Afro-American. AIDS is an equal opportunity employer. There's another, I cannot recall the name of it, that only affects people of Jewish nationality. But it's one of those things that um, ...

M: Or, if it does affect someone of another race, it's very rare?

P1: It's very, very rare.

M: So, those kind of things, I think what I'm hearing is that pretty much y'all think that genetics is really the primary influence ...

P1: I think genetics has a lot more influence than any other thing.

M: Okay. The next thing I want to ask you about is information that you may have heard or read about breast cancer in the mass media. Y'all mentioned talking to your doctors about different health issues, but what kinds of information do you remember hearing or reading about about breast cancer in tv, newspapers, radio, any kind of mass media?

P2: Well you see on television all the time, about Susan G. Komen, the walk for breast cancer, Avon is a sponsor of it, and frankly you hear quite a bit about breast cancer, different ads, things like that ...

M: What kinds of stuff do you remember hearing, do you remember hearing about prevention at all, or genetics, or ...

P2: Yeah, I have, I've heard before how women should give themselves self exams, do self exams, and they always have the 800 numbers you can call to get more information, so I think personally, I think people that are in charge of I guess, of getting the word out about breast cancer, I think they're doing a fabulous job, because ...

P1: I do too. It's nice to see that women nowadays are not keeping their physical problems in the dark. [Participant's husband] and I were talking about this the other night, something was on TV about a young lady who had been raped and her mother was trying to get her to open up, to get her to go to a rape support group, and the daughter just, you know, this is not for me, I can handle this on my own, I'm not going to talk about it, and she was walking out and the mother stood up and said, my name is so-and-so and I was raped when I was 18, and she opened up and told her story. And [participant's husband] and I were talking about how, when I was growing up, and I think I'm the oldest of the three of us, I'm 47, you didn't say "pregnant." My mother and my grandmother always said, "You know, she's 'PG.'" Or, "she's gotten herself 'in a family way.'" When I started my menstrual cycle, it was basically, here, keep this in a drawer. But never really explained to me why this was happening to me every month, or why this was happening to my body. You didn't talk about it, it was dirty. Women didn't share, we didn't talk about this stuff. It happens to you, but you don't talk about it. It's good to see that now we can open up and we can express our feelings and our pains and our aches and our concerns. And it's not just men going around, going, you know, she's ... (motioning with hand). Well there's a reason for that. Our bodies go through so much, and I think it's great that they're putting so much out, not only on television, but in magazines and in movies, and you open an Avon book, and you see it in Avon books, you know, there are people you can talk to now. It's not a dirty little secret, it's something that you can get help for and you can do something about. It's not something we have to keep all closed up and suffer by ourselves. And I think it's great that women can get together and talk about it. It's not pretty, yeah, but if it was happening to men, they would have been talking about it years ago.

P2: That's right! (laughter) I think that a lot of things have started opening up for women, awareness of having children and pregnancy, childbirth, breast cancer, ...

P1: I do too, I do too.

P2: Anything you know that women ...

P1: I think if anything good came out of the women's movement, it was that -- that women finally realized that they've got a voice and they don't have to keep quiet. That great, we still have to do it all, we still have the children, we still do the housework, and now, we have jobs, but we don't have to suffer all of it, we don't have to be the saints and suffer silently, that we can open up and share with each other and talk about it.

M: Well, y'all mentioned TV, movies, magazines. You also mentioned that you've heard about the Avon walk, getting self exams. Do y'all remember ever hearing anything about genetics in the media, like anything about the BRCA gene?

P2: I don't know what that BRCA is. (All participants shake heads no.) I've never heard too much about genetics.

M: OK, so in terms of a source of information on genetics specifically, the media has not really been one for you?

P1: They have not.

M: What about the Internet? Do you ever look at health information on the Internet?

P2: I've gone to WebMD for other things, but not for breast cancer.

M: Okay, but you have looked at it for other things?

P2: Sure.

M: What about y'all, -- and --, do you ever use the Internet for health information?

P1: I have, and I have found it very valuable over the last several weeks. It has given a lot of really good information. It's also kind of reaffirmed Mother's decision to do what she's done, it's just kind of helped me to give her better information to ease her mind that, you did the right thing.
I think it was very helpful.

M: Did you think that the information was trustworthy?

P1: Yes I did. I didn't feel like I was getting snowed, I didn't feel like that there were people out there that were just saying what they felt like you needed to hear, that they really, like they would stress to follow up with an oncologist no matter what you decide, tumor wise, and regular follow ups, so they didn't snow you, they basically gave you the cold hard facts.

P2: I agree with you, I think that, like WebMD, I think that they give you a lot of really good information.

M: So, WebMD for you ...

P2: I've been to WebMD, I've been to CDC ...

M: So you have gone to the CDC. --, what sites have you looked at?

P1: Honey, I honestly do not even remember because what I did is type in the kind of cancer that I was told that Mother had, and I looked at every site I could get my hands

on. And I did find that the information was fairly consistent throughout the sites too, so that was really good.

M: Okay, so did that contribute to the credibility?

P1: It really did. Because I didn't click on one site and get this viewpoint and then click on another one and get something else totally opposite. They were very consistent. So I do think that the information that I was receiving was really factual, and it was very helpful.

M: That's great. It's so nice to have that as a resource, I think. But you basically, if it wouldn't have been for your mom, you probably would not have done that, probably?

P1: I don't know that I would have ever had a reason to. I might have researched breast cancer in general just for information if I felt that I needed to know more about it, but I would never have looked for that specific kind of breast cancer, for a certain kind of breast cancer, because there are so many different cancers.

M: Have your kids ever brought home health information to you on breast cancer, or just any kind of health information?

P2: Oh, yeah, from the school.

M: Okay, but not anything on breast cancer? (Ps shake heads no.) I had some students in one of my focus groups who had actually gotten breast cancer education in high school, and I didn't even know people were doing it that young, and they said they had taken some stuff home to their moms. So is it basically things on their health that they bring home to you, have they ever brought home anything on your health?

P3: It's basically like teenage health-type stuff.

M: So, primarily for them, and then they're just bringing it home to you?

P3: Yeah.

P2: I see a lot of stuff on drugs, teenage pregnancy, signs of drug abuse, things like that.

P3: Yeah.

M: How much do you think you talk about health in general with your family members, spouses, kids?

P2: We tend to talk about health some, but not necessarily breast cancer. My husband was just tested the other day, he had given blood back in July, and someone who received his blood and someone else's blood had gotten West Nile, and they're not certain if the West Nile came from the blood donation or somewhere else.

M: So you've been talking about West Nile a lot lately, I guess.

P2: Yeah, and we still don't know if [participant's husband] has West Nile or not. We just, you know, we talk about a lot of stuff. Especially now that we're getting older. You know that? Now that we're hitting our mid 40s.

P1: I'm finding more and more that health is a big topic in our house.

P2: Yeah, you know, I wake up in the mornings now, and I feel stiff, and I used to be able to just get up, jump out of bed and get going, but now, I have to get my coffee, get my legs going, I'm just not as young as I used to be.

M: So, just kind of every day stuff you feel like you talk about more?

P2: Yes, you know, headaches ... Of course my girls' menstrual cycles is a big topic -- they've both had ovarian cysts lately, so ...

M: Do you feel like you talk more with the girls than the males in the family?

P2: Yeah, because my daughter's 16 and my son is only 12.

M: Okay, so you think it has more to do with their age? (P nods yes.) Okay, which family members do you think you talk with about health the most?

P2: My husband.

P3: My sister.

P1: Mother.

M: Um, I know the answer to this question from you (directed to P whose mother just had breast cancer), but have you ever discussed breast cancer specifically with a family member?

P1: Mother and I had talked about it 10 years ago when her first cousin developed breast cancer. So I would have been 37 and the boys were very young then, [participant's son] would have been 2 and [participant's son] would have been 6. And mother and I talked about it then because of her choices as to what she was going to do and not do to treat her breast cancer, and mother had asked me, what would you do, and I told her then just like I told her a few weeks ago: take 'em off. If it's a choice between my living to see my children grow up and be there for them, and having boobs? I can live without the boobs.

P2: That's right.

P1: I don't want to not be there to see my children grow up.

P2: And about every time I get a mammogram, I think, why don't I just go ahead and take these things off, just go ahead and smash them the rest of the way, put me out of my misery! (Laughter)

P1: I don't think it would take too much effort, the way they squeeze and mash them, then you could just squeeze and mash them all you wanted to. But you know, Mother and I both had said at that time 10 years ago that that would have been our call. And it held true when it actually faced one of us. We'd discussed that in great detail, even before we were actually faced with it.

M: You said you talk to your husband the most about health. Does the subject of breast cancer ever come up with him or your daughters?

P2: Sure. Yeah, it does, you know, we don't discuss it every day, you know, I'm sure if someone in my family was diagnosed with it, that it would be a lot different. But we talk about different types of things. Our biggest thing now between the two of us is overweight and we're worried about diabetes, and there's a lot of people out there with Type 2 diabetes, adult onset. But we talk about it, I do my breast exams. I don't do it as much as I should every month, but [participant's husband] will say, have you checked, and I say yes or no, and it's usually no. But you know what? And I think this is a fallacy on my part, in fact I know it is, I don't have history of breast cancer in my family, so the monthly exam's not ...

M: It's not on your radar screen ...

P2: Right, because my mom, my aunts haven't had it, so ...

P1: Guess what! Even the surgeon couldn't feel Mother's mass. So it doesn't make you safe.

P2: Really!

P1: Found it through the mammogram.

M: --, do you ever talk to anybody in your family about breast cancer?

P3: My sister. About five years ago my aunt got it.

M: So at the time, y'all probably talked about it a lot, I guess.

P3: Yeah. And then after that news died down, we don't talk about it that much, but right after she got it, we did.

M: And is it still mainly your sister, have you talked to anybody besides your sister about breast cancer?

P3: My aunts.

M: How influential, and y'all might laugh at this question, but how influential do you think you are as a source of information about health in general to your family members, and to your children?

P2: Very, I'm very influential. Yeah! Well, yeah. My one daughter was diagnosed with a 7 cm cyst on her right ovary several months ago, and we thought it was her appendix that had burst. But you know, if I don't stay on those kids to go to the doctor, get their sinuses checked out, all their plumbing checked out, everything, you know, they won't do it. Neither will my husband. So I think that I'm very influential.

M: With your kids and with your husband?

P2: Absolutely. My husband will not go to the doctor unless I stand behind him and push.

M: And he listens to you, you feel like they listen to you?

P2: The kids do, because they don't have a choice. (laughter) I don't give them a choice. But my husband doesn't listen too much. I mean, he will if I get mad I guess.

M: What about y'all, -- and --, do you feel like you are pretty influential sources of information, or do you feel like you're always saying, "do it, do it, do it," and nobody listens?

P3: I guess I'm pretty influential, because I make their appointments for them and then take them to it.

P2: But see, at 16 and 12, she has to be.

M: That's a good point. What about your husband?

P3: I'm divorced.

M: Oh, Okay. So as far as your kids, you're pretty much it -- they pretty much do what you say.

P3: Yeah.

M: What about your other family members, like you said you talked to your sister and your aunts when your aunt was going through breast cancer a few years ago, and you get your mammograms early just because you felt like you wanted to start doing that -- do you ever talk to them and try to get to do them to do the same thing?

P3: Yeah I did, but a lot of my aunts are way older than I am, so they just say, well, I don't think I have it, so they kind of base their own opinion on it, and they don't go as often as they probably should.

M: So you feel like you're much more influential with your kids than with your older relatives?

P3: Right.

M: --, what do you think?

P1: My family calls me Dr. [participant states her last name]. (laughter) It's a family joke -- they call me before they call the doctor, and then they call me after they go to the doctor, and go, you were right! I worked for 15 years at Athens Regional, and it's not that I'm any more knowledgeable than anybody, it's just that I'm tuned in to my family. Talking about health issues and medical treatments is something that I've grown up with. My mother has a bad heart, she's on her second aortic valve, artificial heart valve; I had a brother who had multiple birth defects, [participant's brother] was born with a lot of things that you wouldn't want your child to be born with, so we spent the better part of my youth at Emory, at Egleston, at Mayo Clinic. So I've always been around hospitals and doctors and medical issues and it's just always around me, and I just pick up on things, I learn quick. And I did work at the medical center for all those years. I did pick up on a lot of stuff. It's just kind of a running family joke. But they do listen to me every now and then.

P2: Dr. --, meet Dr. Mom. My kids call me Dr. Mom. And I do all of the exams, you know, where I visually look at their skin. My husband's had basal cell cut off his back a couple of times. But I make them go to the dermatologist. And I try to make them wear sunscreen, but I tell you what, when they get to be 16 years old, they don't always do what you want them to. My oldest daughter, she likes to go to that tanning bed, and I am totally against those tanning beds. I just think that they are just horrible for your skin.

M: They are so bad, I think. We could talk about skin cancer all day. I'll save that for another study.

P2: Another dissertation?

M: No! I only want one of those -- please don't make me do more than one! (laughter) Okay, we're almost done, this is the very last part. You know, I mentioned to you that the reason I'm doing this is to get some ideas for how to do my survey. We're thinking about a few different ways to do the survey, and how to get the moms' participation and that kind of stuff, so I want to get your ideas of what you think would work the best. First let me tell you, one of the things we're thinking about doing is offering a web-based version for the moms, and I guess some of the students could fill it out this way if they wanted to, but since the moms probably won't be in Athens we were thinking it would be great if the moms could go online and fill out the survey instead of having to fill out a paper version and mail it back in. What do you think about this idea, do you think the moms would use it?

P1: Most of your students' mothers are going to be computer savvy, I would think. Like, my mother is not computer savvy and would balk at it, but that's my mother. I think

most moms our age at least have a working knowledge of the computer, and most of the UGA students, because their parents are basically middle or upper class, would have that knowledge.
M: So do you think that most of the moms would have access to a computer, either at home or at work?

P1: I think so.
P2: Yeah.
P3: Yeah.

M: We're going to offer extra credit to the students, and so in trying to figure out how to get the moms to also fill out the survey, what I'm leaning towards is that we only give extra credit to the student if both the student and mom fill out the survey, so it's an all or nothing kind of thing. You don't get partial credit if you fill it out but your mom doesn't. And we'll have options for students whose moms aren't available or deceased.

P2: I think it would work.

M: The students kind of thought it would work. But as parents, how would you feel if your kid called you up and said, I'm going to get extra credit if you do this?

P1: Oh, as parents who are constantly pushing our children to do well, oh yeah.

P2: It's just one more thing to fill out for me, I filled out last night five pieces of paper on Laura's oceanographic trip, or something like that, and college-age kids are the same way. You know, their parents are used to filling out all kinds of things, so it's just one more form.

P1: You know, it would be nice if you could do something little for the parents like a $5 certificate to Bed, Bath and Beyond or Bath & Body Works or something like that. But I honestly don't think you would have to do that though. I'd be surprised if any mother would balk at helping a daughter. And again, in this day and age when we as women are opening up and talking more and more about our own health issues, I don't know of any woman who would balk at doing that.

P2: The only thing is as a parent I would like to know the results.

M: Okay. I'll make sure to do that. Also, I definitely would like to get back with you all when the results are in to talk with you all about that. And I will have an incentive for that, I don't know what it's going to be yet, though.

P1: I don't know about the other two but the only incentive I want is [moderator's son]. I want to see [moderator's son]! And I want a pea-pod picture. (laughter)

P2: A massage would be nice!

M: Oh, I also should tell you that we have pretty much decided to have the guys fill out a different version of the survey. We have to provide something for them for IRB

anyway, so I've decided that rather than having them try to find a female friend and her mom to fill it out we will get them to do it.

P1: I know I would be very interested in seeing and hearing what the guys have to say. I know my boys have gotten a real crash course in breast cancer and mastectomies and what's involved and what a woman goes through, and with it being a grandmother that they are very, very close to, it's really hit home. I think they need to be educated.

P2: I agree, I agree. And her boys are teenagers, and I think that's a real good time to start educating them even though their minds aren't geared towards that spectrum of the breast, know what I mean.

P1: In '99 when I had a total hysterectomy and the boys were 13 and 10, they had a crash course in hormones and what they do to a woman, what's involved.

M: -- did the focus group on the guys for me, and he said they had some really interesting feedback, so that's what got me thinking that we really need to talk to the guys too. So hopefully we'll get some good stuff from them, and the moms of the boys too.

P2: Have you talked to [a professor in the department]? Because you know she does the Avon walk.

M: Yeah, you know [a graduate student in the department] did her dissertation on the Avon walk, and since we're good friends, I got to learn a lot about the Avon walk from her. Yeah, like y'all said, you hear lots about it on the news, particularly about the walks.

P2: For the most part for me, my own doctors, they're, you know, every time I've gone in, they're, have you had a breast exam lately, you know, they're very keen and very aware to mention breast cancer.

M: So doctors are still a pretty influential source.

P2: I think they are, but, I think so.

M: I'm pretty much done with the questions I had scheduled. Do y'all have any questions for me about what I'm doing, or just any final comments that you wanted to share?

P2: Are you looking for something specific, or are you just trying to get an idea of women and their daughters and how well they do their exams?

M: I'm not really looking so much for behaviors as people's perceptions and possible ways that we can help people to understand genetics, how genetics works. I'm real interested in family communication, because a lot of the genetics research that looks at genetic counseling talks a lot about how important family communication is. So that's why I wanted to talk to not only our students but their moms too.

P1: We see so many articles in magazines telling us how best to communicate with our children, how to talk to them about everything under the sun, it would be nice to see something about how to sit down and talk to your children about health issues. We talk to them about everything, drinking and drugs, safe sex and all of that. What about, OK son, here's your family lineage, you've got hypertension, diabetes, cancer, ... These are the things you can look forward to, these are the things you need to be aware of as you get older.

M: That's such an interesting point that you make, because in the genetic counseling literature, that is one of the things that they say is really hard in terms of counseling a person, is that so many times, especially the men seem to not know their family history of different things at all. So it's interesting that you bring that up.

P1: And it's very important that they know that, and again, that's a big thing, especially with women who don't seem to care who they have children by. They're not sure of the guy's last name, not to mention what his mom or dad had health wise. That's scary. That's real scary.

M: Well that's kind of what got me thinking, those kinds of things were what got me thinking that I wanted to have a family perspective on my study. Do y'all have anything else? Thank you so much, this has been really helpful to me.

Male Focus Group Transcript
September 11, 2002

M: Greetings. This may seem a little bit unusual because obviously breast cancer is not something that most of you have thought about as a real personal threat, although I guess sometimes males get breast cancer, but it's like really unlikely, one or two percent of all breast cancer. But it may well effect people in your family now, it certainly might effect at some point some relationship or situation in the future. What we are interested in looking at is just your feelings about what you have heard, what you know about it, to what extent if any. You talk about health issues in general, and breast cancer, and more specifically with members of your family or what have you. But before we get going, why don't we first just go around real quick and tell your name in the camera … [Participants give names.]

M: Ok. Let me start with a first broad question. Overall how important of an influence is genetics in determining whether or not a woman might get breast cancer in your opinion? If you don't have any opinion, that's ok too.

P1: I guess I'd have to be honest, I don't really know the science of it, just off the cuff I would assume that genetics would have a lot to do with any sort of disorder, but I couldn't say to a certain extent.

P3: I know that my grandmother died of breast cancer, like three and a half years ago. So like I know that talk to my female members of my family about breast screens and everything. I know that they think there is some link to it, but I haven't seen anyone else in my family have it, but I guess it's still a concern that there possibly could be.

P2: And I had the same situation. My mom came down with breast cancer… seven years ago, eight years ago, I think. She survived, but I don't think anybody else in the family had breast cancer. They've had other forms of cancer in the family… liver, and lung cancer, and skin cancer.

M: Did it strike you as odd that because there was no family history that she came down with it?

P2: Um, I was really young so I wasn't so familiar with the whole circumstance. But I feel that genetics had some play in it but not necessarily the final role in whether you get it or not.

M: So you guys don't have any notion about what percentage you think. What do you think about genetics role in relation to other factors, environmental factors or eating habits? Things like that. Do you have any gut feelings about what role you think those have, versus genetics in terms of their impact?

P1: Well I guess it's easier to see in other forms of cancer environment playing a role. In lung cancer, liver cancer, things like that. So I wouldn't be sure of an environmental role in breast cancer. It doesn't seem like there are outwards things to do per se to either prevent it or bring it on yourself. As it is in other types of cancers.

M: Any different opinions?

P3: There probably is some things that cause it, environmental that I don't know about. I'm not really sure right off hand. I'm sure there is something. That actually does, show something you do or some big sign, I'm not real sure.

M: Let me ask now about the sources of information that you have received about breast cancer. In general do you remember hearing coverage about it?

P2: In health reports. Other than that the news and stuff.

M: Is the television the primary place you've seen it. Or do you remember any specific sources where you might have seen or heard about it?

P2: Well for me and my mom, we got really involved. So I heard a lot more about it from her and the organizations that she has been in. So mine was more on a personal basis, it wasn't necessarily a mass media. People that I know, people that I have met that have siblings or family members that have gotten it, or any type of cancer.

P3: Mine was too. When my grandmother died, my mom did all the cancers walks and stuff like that. I just picked up information, and kind of learned it from that. But I have also seen MSNBC when the release studies and stuff like that. Since I have known an infected person it has all caught my attention more.

P1: I would say mass media, but I haven't had any in my family, so far I've been lucky. Just TV, I'm sure I have read about it in magazines and newspapers.

M: Do you remember anything specific about the stories that you've seen? About the content that they might have talked about?

P1: I remember they talked a lot about screening. I've always talked to my mom, just to make sure that she does regular screenings, just because I've heard that. That's enough for me to hear you have to get regular screenings. I feel like that's the first step.

M: Anything else that strikes you about the information that you've heard?

P3: About four years ago, I guess two months after my grandma had been diagnosed, it had spread throughout her body. They found a drug that they thought might work, so just stuff like that. I guess drugs and spending money on it. I know breast cancer has been getting a lot of money for research and stuff like that.

M: It's interesting how much more money breast cancer gets than, prostate cancer for example. And yet the incidents and the mortality rate are almost identical.

P3: I do remember seeing one study, where it showed where people die from, like heart disease… the top three. And that receives less funding than breast cancer too.

M: How trustworthy do you feel like the information was? Did you feel it was on target, or did you question it a little?

P3: Most of the stuff I heard was from doctors telling my parents. I guess they just trust doctors.

M: Right not from the media then?

P3: That's where I got my basis. So I guess I trust them before the media.

P2: I think that when they start coming out, a lot of times they start claiming every two or so months that something is linked to breast cancer. I think it's a little over covered in that perspective that's the only time you can really discredit their information. One week something causes it, then the next week that causes it, and the next something else causes it too. They just give a long list of what could cause it.

M: Do you find any particular source other than from the health profession itself, in other words, maybe a pamphlet or direct conversation with a physician, that you find as being more credible than something else? About health information in general …

P2: I think a good way that they get it out is Relay for Life. I know that my mom has done it, and I have done it to. That's a very, very effective tool to get information out, and in a very trusting atmosphere. There's a more personal basis than a news program or something.

P3: Stuff like that, where survivors and people who have to deal with dying just talk to each other. I guess that's more trustworthy, personal experience.

M: If you had to rate between different aspects of the media, between say radio, television, newspapers, internet, which one if any do you think would be a more credible source? Or is there any difference?

P1: I guess the only one that I wouldn't trust is the internet, because I fell that it is such a shaky medium for validation on things. I think that sometimes it gets over covered, like everything causes cancer nowadays, but I don't see the media hiding anything. I feel like they air on the side of caution on that one issue, opposed to other things that I think they sensationalize or slain. I think that they try to be straightforward with a health issue like that.

P2: In my opinion, I would actually take information general that I get of the radio more seriously. You don't get a lot of news on the radio, so normally when they do a report on something, it is more legitimate, it's been researched and out there for a little while. Where as you go on CNN, or CBS, or CNBC, or FOX, they try to fill air time with fluff. They have to fill so many hours with it, and sometimes its just ,' they found one gene that could possibly be linked to the next gene that may cause of cancer.'

M: That's interesting. I haven't thought about that, I think you might have a point. Radio usually have real big bulletins, unless its like an all news station.

P2: Unless it like a news radio, like WSB.

M: With regard to the internet, you mentioned that to a large extent you are a little bit cautious about the information on the internet. Are there sites that you do consider the information better, or more reliable?

P3: MSNBC and CNN, stuff like that.

P2: American Cancer Society.

P3: It's a whole lot easier than watching TV. I can, in between classes, go to the library and check on the news that way. Those types of sites, I trust those.

M: Have you ever gone to any of the sites like, CBC or NIH sites, state health sites, WebMD, that sort of things. Have you ever looked on any of those?

P2: I have had to research, not breast cancer, but I was researching something. I had to go to CBC, and other medical sites about diseases… I think they were sexually transmitted diseases, stuff like that. As much as I would trust them, it was very hard to find information on, because it's like a big database and you have to, its almost like searching in a library. It's a little harder than finding, or going to CNBC or maybe the American Cancer Society, something where that's the soul, that's a big issue, you get a lot more coverage on it. Where as going throw millions of studies that CBC has posted online.

M: So is this information overload?

P2: And it's a lot harder to understand too, because they are in full medical jargon.

M: Right, so it's not really made accessible to a lay person then. It's pretty much they expect you to be able to understand that. How about campus organizations, have you ever heard anything about breast cancer, or genetics and health from maybe on campus organizations?

P1: We do Relay for Life, I heard a lot about that through the fraternity that I'm in. We try to make that a big deal. One of the guys in there's dad has cancer right now, and he's very passionate about it. I guess the health center hands out through organizations, in my fraternity they give us… not breast cancer, but testicular cancer… those little shower head things. They hand those out to us every semester, and we put them around the house. We joke about it because it's funny, but it's nice to have it there. I went and got a cancer screening one time, like a testicular cancer screening. We took our whole flag football team before a game one time, just because we thought it was a good idea to promote it in the dorms.

M: Do like Lance Armstrong's case have anything to do with that?

P1: Well I guess so. Someone in that good of shape is gonna end up with cancer, I guess anybody… it's definitely not something that you get from laying around, or being active.

M: Kind of makes you think, doesn't it?

P2: I remember John Kruk's testicular cancer. I lived in Philadelphia, or right outside of it. I didn't even think about it.

M: The next set of questions gets into family communication. We talked a little bit about that here. To what extent do you talk to your family about health issues, and obviously you have both had specific incidents with breast cancer, and it sounded like you talked quite a bit. Is that very typical with regard to health in general, or do you think it was just that particular dramatic case in your family?

P2: I think in my case, most of my family members that have died were from cancer, for one reason or another, normally its them not treating themselves right. It was a very public issue when my mom got breast cancer. She has still got the blue dot, the tattoo that's almost like a constant reminder whenever I see it I think about it. It's something small like that, something that you can see everyday. If she wears something that is low cut I can always see that and sometimes I forget about it, and that always reminds me. WE always are open about friends of the family that have cancer. We talk about it, we keep up with it, my parents are pretty straight up about it.

M: So it sounds like you talk about it quite a bit then.

P2: When the subject matter is turned to that yeah.

M: How about your situation?

P3: I guess we had that consciousness, but it brought it out more when that happened. I think that everyone in my family went and got tested and things like that. We have become more aware, and my granddad's been sick a whole lot longer than that, I guess that finally got him to take care of himself, and now he is in the best shape he has been in twenty years since I've known him. I guess it just makes you wake up sometimes.

M: What about your situation --, is health something you talk about?

P1: Yes it is, my father has high blood pressure, just in my life I have seen him turn his eating habits around, and start exercising more. He had really bad blood pressure for a long time, and just over the past ten years they've cut his medicine way down. At first it was a big deal, so we talked about that, we harped on him to cut down on the sodium. With that being on the forefront, we talk about issues and they're very open about it. My father also just found out that he has type-II diabetes, nothing that you can't live with, but stuff keeps coming up and that keeps a line of communication open. … It's the kind that you control through diet and exercise, so we're always harping on him about his diet.

M: When you think about discussing it, is there anybody in your family that you talk to more about it, or is it pretty much everybody in the whole family?

P1: My parents, my sister, and myself are very close so it's nothing that we cant share between the four of us.

M: Any differences with you guys?

P3: I know behaviors in the family, like smoking, I had a great granddad that died when I was young, and all I remember was he died of lung cancer. I remember the oxygen tubes and everything and that's all I really remember of him. So when my brother started smoking or my cousin, it's like, "don't you remember grandpa?"

M: Anybody in your family you talk with more than others?

P2: Just about health in general, no we don't. In terms of small things, I just talk to my parents, my brothers have lived away from home, so I have been like an only child for the past seven years. So we sit down and talk but not about that, it's usually catching up.

M: How influential do you think you are as a source of information, and as a source of motivation regarding health? We've talked a little bit about urging your mom to go and get screening, or raging on your dad for eating cookies. Talk a little more about that, do you feel like you have an impact on them?

P1: Yeah, I do. Just because our family is so close knit, I think that I have a lot if impact. Especially when I go home we spend a lot of time together. And they are really good about it, but me and my sister are really forceful about it. They are too, my mom's on my dad a lot and he is on her, so it pretty much balances out.

M: How about your situation?

P2: We talk about the weight thing, and my mom has joined a gym, but my dad was in the military for twenty plus years, so I think he is done with the slim trim. He enjoys his beers every night. My brothers and I hassle each other, but its mostly just kidding about it, we don't worry too much.

M: How about you?

P3: The same stuff that they were saying is the same in my family.

M: You don't feel like you are a huge motivator?

P3: They take care of themselves, My brother smoking is the only thing I guess I can try to stop, but he is so hard headed he won't stop no matter what I said.

M: I did a lot of stupid things growing up, but for some reason I never got into cigarette smoking. I tried it once and didn't like it much. Moving into the last section here, part of

what [the researcher] is going to do in her study is a survey that she is going to give to students in another class, its an intro class. And it's a survey that both they will fill out and their mother or closest female relative will too. And one of the things that we are thinking about doing is offering it in a couple of different ways. One is like a paper pencil thing and fill it out. Another way is to have a webpage survey that they could fill out. What do you think about that, do you think that having an alternative would be helpful or do you think that it wouldn't matter?

P2: If you can get people to go to a website, that is a lot easier than having to sit down and write down. This way you could sit down for five minutes, type on the internet and press submit. That way it would be a lot easier to get your closest of kin, or family to do it.

M: In your own situations, how many of your parents have access to the internet?

P3: My parents have access but they rarely use it.

M: So they have it but don't get on it much. So you think they would in a situation like this if you were in a project and you were gonna get extra credit just to fill it out?

P3: My mom probably would just because its about breast cancer.

M: One of the things that as I talked about, is getting course credit for this. I'm wondering, if you think that would be a good incentive for the mothers as well. If that would get them to do it, if their son r daughter was getting course credit for it?

P1: Yeah.

M: Anything else that you can think of that might be an incentive in addition to that, that might get them to do it?

P2: I think you would get a little less apathy with parents because its actually an issue that concerns them. So if you offer an educational opportunity they might be more willing to do it. they might take time out of their day to do it.

M: So providing a pamphlet or something on the subject at a later point? How interested do you think they would be in in giving a summary of the research findings? Do you thin they would be interested in that? If they took part in the survey, if they were interested in the results after the study? Or do you think they could care less?

P2: Set up a quiz maybe, and have them answer what they believe is would be and chances are that they would be … breast cancer might be a public issue that they know the statistics on it and the information about it but I find that that's pretty good. You ask them a few questions, like Jay Leno on the sidewalk, where he asks them a question and it makes them look like an idiot…

P1: "Jay-walk"

P2: Yeah, "Jay-Walk." Then you realize that you don't know much about this.

M: Obviously this is probably going to more directly involve female students than male students, even though most of the female students that are in class with me are no really the prime age to get breast cancer, they will be. Obviously they're a major focus on this study, but we also feel that the males are an important part of this study because you are a part of a family. You certainly have a degree of influence in trying to urge people to go get screened and so forth. What do you think would be a fair way to involve male students, to have them go ahead and fill out surveys as well, and get their mothers to do it, or would there be some other way to get them involved? That's one thing that we want to make sure of, if you are going to give extra credit, we want it to be equitable.

P3: What would be a typical question on a survey?

M: One thing we'll ask knowledge questions. In general, what impact does genetics play in typical breast cancer? There are figures on that, but it's not cut and dry. There are a lot of differences if you have had primary family members who have had it. It's almost a case by case basis in terms of direct impact. But we would ask knowledge type questions like that. We would probably also ask questions that would go into questions that maybe go into some of the things we talked about tonight, in terms of the level of involvement they have in heir families discussing health in general, and breast cancer in general.

P3: Questions like that would be fair to ask guys, because I think males have to take responsibility as well. They have a part, and they need to make sure females, wife or whatever, gets appropriate health screenings.

P1: Just like you saw here, with the two guys here with intimate family members have had that, so their interests … so out of our class two guys interests had already been peaked in the subject so you couldn't tell how many in a larger class. I think just getting guys responsible, if you made a point of that, it's just as important for them for the girls ten years from now to start getting screenings. It would be important for us if we're married tem years from now to make sure. Maybe hand out a pamphlet on testicular cancer too, if you said the number are roughly the same. I think everyone knows how important breast cancer awareness is, but it think testicular cancer doesn't get the same media play as it does. But if the numbers are similar, that struck me when you told me, I would take a pamphlet and read it.

M: It was actually prostate.

P1: That's what I meant… sorry.

M: Testicular cancer is actually a more relevant concern for you guys, because that's the incidents tendency in people in their twenties and thirties for that disease, which is scary. Most of the time, prostate doesn't hit men until they get up into their sixties and seventies and so forth. But I'm a case and point when I had it, probably when I was in my late thirties I when it actually started, the size of the tumor and all that. So you

never know. What do you think about another alternative about having guys in this particular class go out and recruit another female student they know, and get that student and their mother involved in it as an alternative. Do you think that is legitimate or would it be better in your mind for them to actually complete their own surveys and have their mothers involved.

P2: I think every guy out there has either a girlfriend or a girl that he cares about, and they might be in the same class as them or they might not be. I would be willing to take home a survey to my girlfriend and have her mother fill it out because that's someone in my life that I care about.

P1: You don't have a girlfriend!

(laughter)

M: You can't narrow it down to just one.

(laughter)

M: So the neither one it sounds like would be legitimate.

P3: As long as the guy is actually involved in the process, don't leave him out because he needs the information just as much as women do.

P1: You can still get your mom to do it either way. The information is just as important on a guy's part as it is on a girl's part, because both are either going through that, have been through that, or will be going through that. You're still hitting a target audience with the moms.

P3: If you do that, if you get a girl to get her mom to do the survey, I know I would want my mom to do the survey as well. You could find out if … I'd get my girlfriend's mom to do it and get my mom to do it.

P1: I have a girlfriend too. (laughter) So I would get her to fill it out as well.

M: Any other thoughts that you have about things that we've talked about? One question that I will follow up on that I'm curious about, you guys touched on it a little bit when you talked about a lot of studies that come out. To what extent do you guys find it frustrating that you will see a lot of studies that seem to contradict one another?

P1: I think it is really frustrating, because it seems like everything causes cancer. Everything, the air you breath causes cancer. There's nothing you can do about that. Plastic causes cancer, but you don't want to be bad to the environment. "Don't eat red meat," "do eat red meat." "This much is good for you, but anything more…" I almost think it's ridiculous to where it's almost pick your own poison. It's almost like you can pick which cancer you are going to be most likely to get. Then you just go with it. Like, "OK. I'll take skin cancer, this cancer, and this cancer. Those will be my three." "I won't

smoke, but these three are the ones I'll have to worry about." That's just a personal rant. Everything causes cancer.

P2: And they say that you are supposed to have a glass of red wine a day to make you healthy, but if you have two you're gonna die ten years earlier. Plus if you have a beer a day, it's supposed to be good for you, but if you have more than that you are gonna die.

M: There's going to be a lot of dead college students.

(laughter)

P2: Exactly.

P1: Being out in the sun too much…

P2: Yeah look at me, I'm a prime candidate for skin cancer.

M: Well, I appreciate your time, this is definitely helpful. I hadn't anticipated to have two out of three with family history. It's real interesting to hear your perspectives, because it obviously a real dramatic personal way. The one good thing about this disease is that you can survive it. Both of you seemed to have a happy story about that which is nice, which isn't always the case for some who don't get screened early enough. I appreciate your time.

Female Students Focus Group
September 11, 2002

[moderator and students introduce themselves]

M: The first topic we're going to talk about is the role of genetics in the development of breast cancer and my first question to you is a pretty broad one. How important of an influence is genetics in determining whether or not a woman will get breast cancer? So, in other words, in general, how much do you think a woman's family history affects her personal risk of developing the disease?

P: I think a lot.

Yeah, I would say a lot.

I've heard a lot, and I've heard it affects every other generation.

M: Ok, when you say a lot, do you think that that is a certain percentage? You said every other generation, if you just had to guess, what percentage do you think it would be in terms of what a woman's personal risk would be?

P: Like, you're 50% more likely.

M: Ok, so you would say that 50% of breast cancers are caused primarily by genetics?

P: No, I would say you're chances are like 50% higher.

Like, everyone should be careful, but if it is in your family, you should be extra careful.

Right, yeah.

M: Ok, how do you think genetics compares to other factors like the environment or personal behaviors in influencing the development of breast cancer?

P: I think genetics are held higher than like personal behavior.

Well I think like keeping an exercise behavior and eating right does help prevent it I guess but you have a tendency to do that you know . . .

And genetics is easy to like put a finger on. It's harder on your personal habits.

M: That's an interesting point.

P: Like, with breast cancer it's harder on personal habits. Like lung cancer maybe. Like smoking directly contributes. Yeah.

M: Interesting. So what about, do y'all ever hear about screening? You know, if a woman has regular mammograms, or does self-breast exams, do you think that factors in in terms of the personal behaviors?

P: Well, like I have a friend who found out she had breast cancer. She had just had a mammogram like 2 months before she got diagnosed, and it just didn't cover it so like I guess sometimes I get scared to death but it doesn't always cover it.

M: Anybody else have any ideas about how genetics might compare to other factors? --, you're kind of quiet.

P: Well I was just thinking about my aunt, well she's actually my ex-aunt. She had been doing her regular mammograms, she had been fine. And then a year, like, she went back the next year to a different doctor, and he was like you've got breast cancer and at the hospital they had misplaced her file. They were supposed to call her and tell her. They had misplaced her file.

M: Should be a lawsuit.

P: Yeah, it was a lawsuit, and she won and everything. It was just a bad situation cause she had noticed a lump when she had gone the last time and had it tested. Yeah. And they told her everything was fine, so.

M: That's amazing. I guess that's a good example of how you can do, how personal behaviors are appropriate. Do y'all have any other comments before I move on to the next topic?

P: I think it's important for women to make an effort to get screened every year and do self exams because if you have breast cancer you'd be likely to at least catch it maybe in the earlier stages so it's not so hard I guess

M: Ok, good point. Anybody else? Ok, I'm going to move on to the next section in just a second, I just want to make sure this is taping. I just want to make sure . . . (tape goes off and back on). Are you kidding I have my files saved in like 48 different places. But then that's bad because I can't remember which one I worked on last, you know? Ok, the next section is on mass media and Internet sources for health genetics and breast cancer. I want to just talk to you briefly about information you might have heard or read in mass media sources. First, in general do you remember reading in general health information in the mass media?

P: Just general?

M: Uh huh, just general health information.

P: Oh yeah. Yeah.

M: Ok. Um, what kind of information have you heard or read?

P: Exercise. Prevent certain kinds of things with certain kinds of foods.

Um, the studies I heard about the . . . lymphoma replacement surgery for women with breast cancer, that's been a hot topic.

Birth control. Yeah, birth control. Stuff like that.

M: I know it's all over the place so it's almost a silly question, but any other health information you remember hearing about in the TV or newspapers? Have yall been hearing about the West Nile stuff?

P: Oh, just health in general?

M: Yeah, just health in general. Seems like that's been everywhere to me.

P: They've had a lot of AIDS research that's been actually successful lately. I read about it in Paris that they actually found something that stops the disease.

P: Oh wow, Paris.

P: No, no it wasn't actually in Paris the city, but the magazine. No, I actually did go to Paris this summer, but I didn't read in French. But, there were like developments in AIDS research in Paris.

M: That's interesting, I hadn't heard that.

P: We've had a lot of West Nile stuff in Memphis, my mom said, well there's a lake in our neighborhood that our newspaper, it's not a good newspaper, but um, the headline one day was "Chicasaw West Nile Hot Zone" which is where we live.

M: Oh my gosh.

P: Like on a map, circled our neighborhood, my mom said that to me, it was just like (laughter) Oh my gosh!

M: Is there anything else that y'all remember hearing? I mean it seems like pretty much everybody, I mean you all have heard health information from many sources, or read it from many different sources.

P: There's also been a lot of um like obesity studies.

M: Yeah, like now that I have a child, I notice so much more about things that are linking, even when babies are very little. Like even when they are 2 months old, you can start getting this predisposition to eating disorders.

P: (laughter) So much stress as a mom.

M: It's too much. (laughter) Um, anybody else want to chime in? Ok, my next question is, I think some of you mentioned this, so if you could just talk a little bit more, if you remember hearing or reading anything about breast cancer specifically. So, I think you had mentioned, --, hormone replacement, you had heard something about it.

P: Well, I'd heard one study that women who take hormones are more likely to get breast cancer. Then, I heard another story that counteracted that. It was like no, no, no it doesn't cause it. So, it's a little confusing.

M: Ok, somebody else said birth control. Was that you, --?

P: Yeah, just that you see it . . . Wasn't there something about 6 months ago about mammograms, they was they improved how they give mammograms?

M: I didn't hear that. I know that people talk a lot about how technology should be improved. But I don't know, I hadn't heard that.

P: I heard something, I know it was a long time ago, I don't know how much truth is behind it or not, but I heard something about bras, like if you wear bras a lot, like sleep in them and everything, that is heightens your risk of breast cancer.

Yeah, I think I heard that too. Something about it like strangles them.

M: Is it because it cuts down the circulation?

P: Yeah. I don't know why, I just heard about it. I don't know how truthful.

M: Where do you remember? Do you remember if it was on the TV?

P: I don't remember if it was so much from the TV or like other friends.

M: Oh, ok, so that wasn't specifically from the media?
.
P: Yeah, well I don't know, somebody might have got it from there.

M: Ok, we think it might have started there. And y'all both heard that in high school? And you live in Memphis, and you live in Marietta? That's wild isn't it? Anybody else remember hearing anything else or reading anything about breast cancer besides what we've already talked about?

P: I read, I think it was an article in *Cosmo* that it was a lot more in like younger girls, breast cancer was showing up. Lots of stories about that.

I remember I watched The View, and they did this huge thing on breast cancer. I mean like the whole month, like breast cancer awareness month.

M: It's October.

P: Oh, ok. (laughter) But I don't remember whether I learned anything but it was around.

M: Yeah, cause that's everywhere. I remember seeing like Lifetime, that channel, had like a pink ribbon during October, so it's really there all the time. Anybody else? Do you remember hearing anything specifically about genetics in the media? Any news reports about it or anything like that? Ok, let's see, for those of you who said you do remember hearing stuff, or if you don't that's ok, do you remember, like I mentioned seeing it on Lifetime, do you remember if it was like local, more of an entertainment program, a talkshow, does anybody remember specifically where you heard it?

P: I think the Today show had it like their second or third hour, like it wasn't during their one hour, but during their later hours.

P: I remember seeing a special on Oprah. And, actually, someone came to my high school and talked about it.

M: We'll get to that, so save that thought. We'll talk more about these other sources too. Let's talk about Oprah, what do you remember hearing on Oprah?

P: I don't remember anything specifically, but I remember seeing a couple of shows on it. It's just about women, like Lifetime's pretty much a women's channel.

M: Ok, let's see. How trustworthy do you think this information was? So, in other words, did you believe the information that you heard? And we're going to come back to the high school friends and the person who came to talk to you. What I'm primarily talking about it how trustworthy you felt the information was from the mass media?

P: It wasn't very specific. And since it was told like for the betterment of everybody

M: Ok, do you remember if they quoted research or did that have any influence on how credible you thought the information was or was it just that since you heard it in the media so you trusted it.

P: I remember they had a doctor to show like research or a study shows.

M: Ok, anybody else?

P: Like I'll read in magazines like they have a doctor who answers questions.

M: And you think that adds credibility?

P: Yeah, cause if it was just like a magazine writer …

P: Yeah, or they'll interview the girls that had it …

M: Ok, that's an interesting point. So, you feel like if they actually have women that had breast cancer talking then that helps?

P: Right, cause if like I hear a statistic that a greater number of girls ages 20-25 get breast cancer now, I may be like ok, maybe 2 get it. But, if there are like 5 girls in one magazine, then it's like oh, well, it happened to them, maybe it could happen to me.

M: That's interesting, anybody else? So pretty much overall you felt like it was trustworthy. There were no times you were like, that can not possibly be true. Ok, let's see, now we're going to talk about the Internet just a little bit. Do you remember reading anything about health in general on the Internet?

P: Yeah, I mean there's like a subcategory on AOL or Yahoo or whatever.

M: So, you don't ever visit like the health sites, like WebMD or any of the other health websites?

P: No. No …

M: Ok, that's good to know. Let's see, so you would probably also not remember reading anything about breast cancer specifically on the Internet.

P: No.

M: Ok, this one is specifically about local. Do you remember hearing anything about breast cancer on campus or from student organizations on a college campus? But we can talk about your high school experiences too.

P: Wasn't there like a Race for Cure thing?

P: Relay for Life, that's for like overall cancer, and then we have a Prevention Breast Fest, in like March or April. Isn't there like a walk too?

P: There may be a walk, it's like a whole week thing.

P: My sorority, the Breast Cancer Foundation is our philanthropy. So, we have a softball tournament in March and in October we normally give out shower cards.

M: Well that's neat, I didn't know y'all still did that. Ok, can you talk a little bit about that?

P: I've got one.

P: Yeah, the ones we give out are just how to give yourself a breast exam, and at the sorority house, they are in all the showers.

M: Who do you give them out to when you give them out to people?

P: Well we give them to all the sororities to hand them out, then we'll go to dorms, a Wal-Mart, or maybe a grocery store to hand them out.

M: I'd love to see if I could get some pictures of that. We'll talk later. Um, so you actually participate in giving out educational information, and you hear a lot about the things that raise money for breast cancer. Besides --, do any of you remember getting actual educational information or primarily just we're having a race to raise money and this is why we do it.

P: I think the stress in on more educational.

P: Well, in my high school, they gave everyone fake boobs (laughter). Yeah, like plastic boobs.

M: I know exactly what you're talking about, they have little lumps in them.

P: Yeah, it led to a lot of jokes, but they also gave us those shower cards.

M: Ok, was it the school nurse?

P: No, I think it was like an organization, like we got out of school, they had an assembly for women. Yeah, and they gave us all fake boobs. And they talked about BSE as they called it.

M: Yeah, Breast Self-Exams is what BSE is. It's confusing because BSE is also the name for the disease that causes mad cow disease. When all those mad cow announcements were going around, I was like, Oh, no.

P: Yeah, but it helped a lot. Calling it BSE made it more of a household thing, it was catchy. Like, it's BSE and we're doing it. They basically told us to familiarize ourselves with our breasts

M: Ok, good point. That's interesting. Participating in that kind of an educational program, where did you go to high school?

P: [gives name of home town]

M: Ok. So we have one experience with college education and one experience with high school education and y'all have heard lots about the fund raising activities.

P: I went to an all girl's high school and every year our whole school did Race for the Cure. We'd have a speaker, but I can't remember any of the specifics.

M: But someone did come and talk to you at that point.

P: Yeah, cause it was embarrassing but my dad is a gynecologist and one year he came and talked to us. So, it was like --'s dad gave the breast talk. (laughter) I still haven't recovered from that year. He also gave the sex talk for our brother school so that was great.

M: That's funny. So, the next question is the information that you heard, primarily the educational information, did you think that it was credible?

P: Yeah.

M: Ok, so do y'all have in-services where people come and talk to you about how to do breast self-exams?

P: Yes, we always have someone come and talk to us, and we also have several members whose mothers have had breast cancer, so they come and talk. We had a brunch where we had one mother come talk. And then one mother who's a nurse and has had breast cancer.

M: So y'all do a lot of educational stuff. And that's primarily for your sorority right? Ok. So you felt like that was pretty credible. Credible because it was sponsored by your organization or credible because of the people who came to talk or a mixture?

P: Probably a mixture. I know especially having the nurse with breast cancer come talk. She shared her experience to us . . .

M: So it sounds like in y'alls experience, when people who've actually had the disease come and talk to you that it really enhances the credibility of the message. Ok, that's great. Thank you. I think we're ready to move on unless anyone has any more comments or questions about this. The next topic is family communication about health, genetics, and breast cancer. So we're interested in how much you talk about health issues with your family members. Since your dad's a gynecologist, you probably (laughter). So, just to begin, in general do you think you discuss health matters with your family members a great deal, once in awhile, or never? And we'll just kinda go around the room … Would you say a great deal?

P: I'd say a great deal just because it's almost too much. It's like garbage, I let it go in one ear and out the other. On the other hand . . . (laughter)

M: So, it's primarily your dad that you talk to?

P: Well, he's the one that'll get on me just because college life is so unhealthy. Like he sends me calcium pills by the truck load. When he comes to town, I always have an entire shelf full of calcium pills.

M: How about your other family members, do they participate?

P: Yes, just to be healthy. And my grandmother had a mastectomy (is that right?) She doesn't talk about it just because she doesn't talk about stuff like that but um, my mom will always remind me it's in our family.

M: Ok, that's great, thanks. How about you, would you say you talk about health a lot in your family, once in awhile, or never?

P: Um, well my mom's a nurse, and my oldest brother is a radiologist, so we have that medical side. But, I've never talked to my mom about breast cancer, heart disease runs in my family so we focus more on that than the whole breast cancer thing.

M: Well that's understandable if heart disease is what runs in your family, that is what would be the topic of conversation. Would you say your mom?

P: Well my grandmother has always had far more time. She's been real sick, so I've always just talked about it with her.

M: And do you ever talk to your radiologist brothers?

P: They just talk about everything (laughter)

M: Especially, do they do mammograms?

P: I don't think so. We don't talk about breasts or anything, they talk about stuff that's above my level.

M: --?

P: Um, we don't really talk about it that much, my mom was a . . . so she always talked about breast cancer and then when that happened to my . . . she talked about it more.

M: Just at that particular time?

P: Yeah.

M: So you don't really talk about health that much with your family? There's no right or wrong answer here, I am really just curious.

P: No, I mean my mom's always been into medicine, making sure we were ok, things like that, but no.

M: So she says take your vitamins and stuff like that but no other health issues.

P: Yeah, cause breast cancer hasn't run in my family, so ...

M: So you feel that's probably why you haven't talked about health issues that much?

P: Right.

M: Ok, --?

P: That's exactly what I was going to say, I talk about health issues with my mom but not a great deal because no one in my family had any problems.

M: Oh that's great. You're lucky, maybe they're just not old enough yet. Look what happened to my husband, in one year he lost 3 grandparents. When people get old ...

P: I know it's great. But, my grandfather died when he was like 80, I think he had cancer of some kind but it wasn't like he was struggling with it, everybody knew it was a matter of time, but other than that I mean ...

M: So you mostly talk with you mom?

P: Yeah.

M: --?

P: Um, we talk about health in my family a good deal because my mom has had like 15 lumps drained, like the cancer they just have to get out. So, like every year, or 2-3 times a year, she has to go to the doctor. And it's very painful to completely drain them. They are very hard knots.

M: So she gets cysts?

P: Yeah they're cysts. And my dad has heart problems, and my cousin was diagnosed with leukemia. So my whole family, we're like how are you feeling?

M: So you feel like y'all talk about it a lot because you have so many health problems in your family?

P: Yeah, like my dad had an irregular heartbeat and was on a list for a heart transplant and then it just went away. Like 3 years ago, it got on beat and stuff.

P: It's like related to whatever is going on. My cousin's doing better, so not everyone is concerned about everything, just what is going on at the time. So, mom and I talk about stuff and then as soon as she finds out about her lump, it becomes kind of important.

M: Great. Last but not least?

P: Um, well my grandmother had breast cancer, so my mom's pretty much sat me down and told me, you're going to have breast cancer. She's not really worried about it because she still thinks it's something that only happens when you're like 60 or whatever. She doesn't talk about it a lot with me, she's not like go get a mammogram! Or anything like that she's just like you need to be careful about this and particular about that. The other day, she was like, I have to go get a mammogram, I found a lump on breast, well actually I'm not the one who found it (laughter). Yeah, as far as health goes, I've always been pretty healthy so she doesn't really worry about me in that way.

M: Do you talk to her about things? Do you ever?

P: Well, my dad never goes to the doctor, so I'm always like

M: so you bug him to go to the doctor?

P: Yeah, it's like he only thinks about himself like well I don't mind if it happens to me but then I'm like, well dad think about what would happen to me if something happened to you, like that's what gets him going if I say something like that. My mother's had a lot of health problems, so she's comfortable going to the doctor. It's actually my dad's mother who had the breast cancer. And she gets mammograms like every six months. She has such small boobs, she's actually the one who told me about the mammogram technology

M: Oh so she went and it was better?

P: Well she read about it in the paper. She was like I'm so excited, next time I get my mammogram it's going to be a lot better.

M: That's interesting, it sounds like you talk a lot about health in general. Have you ever, and this didn't come up so I'm guessing probably not, but have you ever specifically discussed genetics and breast cancer with a family member? Well, you said you mom sat you down and said you're probably going to get it.

P: Well my mom has discussed that she's just waiting on one of her lumps to be cancerous because she's had so much, they have to send them off to be tested and the next three days she's always like this is it.

M; And she feels like that is increasing your risk as well so yall have actually had conversations about that?

P: Yeah.

M: Ok, that's interesting. Anybody else ever talk about genetics and breast cancer with your families?

P: Well we don't talk about it specifically, but I've learned to be more careful just because it is in my family. They say to me be extra careful.

M: And when they say be careful, that just means do your breast self-exams?

P: And go to the doctor, like take it seriously.

My grandmother will just remind me.

M: Do yall ever ask your moms or your female family members what types of screening they've had? Or is it more the older relatives sort of counseling you?

P: My grandmother refuses to get a mammogram and we always rattle her about that. No amount of coaxing can get her there, it's like a lost cause.

M: So you do try to bug her?

P: Yeah, we don't even try 'cause she's so stubborn, she just won't.

M: I think, --, you and -- didn't say anything. So y'all have never talked about breast cancer with your family members?

P: Well, sure I have but only when it comes up like filing out forms at the gynecologist, I always ask my mom and she's like no or whatever.

My mom, I guess since she's a nurse and works with doctors and everything, she's so bad about going to the doctor.

M: They are the worst cause they diagnose themselves.

P: She's had 5 kids, so I guess she thinks whatever. And anytime I'm sick, she has no sympathy like at all. Anytime I said I felt so bad, didn't need to go to school, mom would say oh --, you just need some rest and to drink some orange juice. She deals with sick people every day so we don't really talk about it.

M: How influential do you think you are when talking to other family members, like you telling your grandmother she's going to die?

P: She's stubborn and doesn't really care.

M: So, do you feel you're very influential in terms of a source of information about health to your family?

P: I get on my mom just cause she never thinks about herself in that way, not just about breast cancer, but just you know, mom should do this. Not even big issues, just like, mom you know you shouldn't drink 12 Diet Cokes a day.

M: Do you feel like she listens to you? Like does that have an impact?

P: I think so, I mean, she'd never tell me it did, but I think it does.

M: So the way you persuade you dad is to say well think of what would happen to me? Do you feel like that has an impact?

P: I think it does just 'cause he's my dad, but yeah.

M: Ok, anybody else? Ok, this is the part I wanted to ask y'all about any suggestions you have for the survey methods and incentives. I mentioned at the beginning of the discussion that your responses will be used in helping us develop a survey for college students and their moms about breast cancer and genetics. We're considering a few different ways of doing the survey so we want to get your ideas on what would work best. One of the things we're thinking about doing is offering a web based survey as

well as a paper and pencil survey form. Do you think offering this as an alternative would be helpful?

P: Yeah, especially moms.

M: Ok, why do you say that?

P: Being out of state I guess, and my mom's real busy, and doing something like that would be easier for her. To have to mail it to them, have them fill it out and mail it back to me, that's just a lot of work.

M: Ok, how many of your moms have access to the Internet? Ok, so 5 out of the 6, ok. Ok, so for your mom, paper and pencil would be the way to go

P: Well, she doesn't do surveys.

M: Ok, so for the rest of you, you think the web would be easy? To go to a website and fill it out, you think they would rather do that then have to mail it back it?

P: Yeah, and I'd probably use the website too.

M: Ok, we're going to offer course credit to students who complete this survey. What do you think would help facilitate getting the moms to complete the survey as well? What I was thinking is that the students only get extra credit if both the students and the mom fill it out. Do you think the moms would do it?

P: Oh, yeah.

P: What about the kids who don't have moms?

M: We're going to have an alternative for them. Like, with a female relative like 40 or older. Do you think that's fair?

P: Yeah.

M: I'm going to make sure those people won't get left out. Any other ways to get the moms to fill out the survey?

P: I think that's a good way unless you get them all gift certificates or something.

M: Ok, send them some money, ok. Any other suggestions or incentives? Ok, we're also trying to decide how to involve the male students. For Institutional Review Board to approve a study, you can't leave anybody out. If you give credit to one group, have to do it for everyone, that's just fair. We've been considering having them fill out a different version of the survey, having them recruit a female student and her mom to complete the survey. As students, what would be a fair way to involve them?

P: Maybe have them fill out a different version, 'cause if I was the girl they recruited, I'd want the credit.

M: Ok, that makes sense.

P: A different version, more about awareness, like do you know anyone who has breast cancer? Or how do you think about breast cancer in relation to a loved one? Or like with your girlfriend, or your wife? Do you know what steps to take about breast cancer?

M: Ok, great, thanks. Before we wrap up, do yall have any other questions or suggestions? Ok, well thank you so much, this is wonderful. Yall have given me some great suggestions. If yall have any questions about this today or the research, obviously you can all get in touch with me, [researcher's major professor] has my number or you can ask him if you want to talk about it some more or if you have any questions later on. Either one of us will be more than happy to answer any questions you may have.

Appendix C: Survey Instrument

Section I. Genetics and Breast Cancer.

I 1. In your opinion, what is the chance for any woman to develop breast cancer during her lifetime? (for example, 1 in 5, or 1 in 20, 1 in 100)

My estimate is that 1 in _____ women will develop breast cancer during their lifetime.

OR, if you prefer, you may state your answer in a percentage:

A woman has a ____ percent chance of developing breast cancer during her lifetime.

I 2. In your opinion, what percentage of all breast cancers are caused by a gene mutation?

____ percent of all breast cancer cases are caused by a gene mutation.

I 3. In your opinion, what percentage of all breast cancers are caused by environmental factors (such as where one lives, smoking, drinking, diet, exercise, birth control pills)?

___ percent of all breast cancer cases are caused by environmental factors.

I 4. If a woman carries a gene mutation associated with breast cancer, what do you think is the chance that she will pass the gene mutation on to any child she has? (If you are not sure, provide your best guess.)

____ percent chance that she will pass the gene on to any child she has

I 5. If a man carries a gene mutation associated with breast cancer, what do you think is the chance that he will pass the gene mutation on to any child he has? (If you are not sure, provide your best guess.)

____ percent chance that he will pass the gene on to any child he has

I 6. Have you ever heard of a gene called "BRCA1," "BRCA2," or "BRCA3"?
____ yes
____ no

Section II. Media Coverage of Breast Cancer Genetics.

II 1. I have read about breast cancer in newspapers or magazines:
____ never **(If never, skip to question #II 8)**
____ seldom
____ sometimes
____ frequently

II 2. I have read about the following topic(s) related to breast cancer in a newspaper or magazine **(check all that apply):**
____ breast cancer of a celebrity
____ breast cancer of a person other than a celebrity
____ breast cancer screening recommendations (age guidelines, recommended practices)
____ issues regarding effectiveness of breast cancer screening practices (mammography, clinical breast exams or self breast exams)
____ stories about women who had a gene that predisposed them to breast cancer
____ statistics about how often genes cause breast cancer
____ stories about how genes play a role in breast cancer
____ environmental factors related to breast cancer
____ other topic (please list)_____

II 3. I have read about breast cancer in the following newspaper(s) or magazine(s) **(check all that apply):**
____ Atlanta Journal-Constitution
____ Other major city newspaper, such as New York Times
____ National newspaper, such as USA Today
____ other hometown/local newspaper (city or county)
____ Red & Black
____ organization magazine, such as sorority/fraternity magazine
____ Women's magazine, such as Glamour, Good Housekeeping
____ News magazine, such as Time, US News and World Report
____ other newspaper or magazine (please specify)_____
____ don't know/can't remember

II 4. What news or popular media sources of information on breast cancer are most <u>important</u> to you? Please rank the top three sources you checked in question #II 3 above in order of importance, with 1 being the source of information that is most important to you, 2 the next most important. **(If you checked less than three sources, rank only those checked.)**

1_____
2_____
3_____

II 5. What news or popular media sources of information on breast cancer are most <u>trustworthy</u> to you? Please rank the top three sources you checked in question #II 3 above in order of trustworthiness, with 1 being most trustworthy, 2 being the next most trustworthy. **(If you checked less than three sources, rank only those checked.)**

1_____
2_____
3_____

II 6. In general, how confident are you that the information you read about breast cancer in newspapers is accurate?
____ not at all confident that the information is accurate
____ more unconfident than confident that the information is accurate
____ neutral; neither confident nor unconfident that the information is accurate
____ more confident than unconfident that the information is accurate
____ extremely confident that the information is accurate
____ I have not read about breast cancer in newspapers.

II 7. In general, how confident are you that the information you read about breast cancer in magazines is accurate?
____ not at all confident that the information is accurate
____ more unconfident than confident that the information is accurate
____ neutral; neither confident nor unconfident that the information is accurate
____ more confident than unconfident that the information is accurate
____ extremely confident that the information is accurate
____ I have not read about breast cancer in magazines.

II 8. I have seen or heard about breast cancer on television:
____ never **(If never, skip to section III)**
____ seldom
____ sometimes
____ frequently

II 9. I have seen or heard about the following topic(s) related to breast cancer on television **(check all that apply):**
____ breast cancer of a celebrity
____ breast cancer of a person other than a celebrity
____ breast cancer screening recommendations (age guidelines, recommended practices)
____ issues regarding effectiveness of breast cancer screening practices (mammography, clinical breast exams or self breast exams)
____ stories about women who had a gene that predisposed them to breast cancer
____ statistics about how often genes cause breast cancer
____ stories about how genes play a role in breast cancer
____ environmental factors related to breast cancer
____ other topic (please specify)_____

II 10. I have seen or heard about breast cancer on the following television sources **(check all that apply):**
____ local news (local ABC, CBS, NBC, FOX affiliates)
____ national news (ABC, CBS, NBC, FOX, MSNBC, CNN, etc.)
____ local programming other than news
____ national programming other than news
____ Public broadcasting program or news
____ cable/satellite (such as HBO, Lifetime, Discovery, The Learning Channel) movie/program
____ other television (please specify)_____
____ don't know/can't remember

II 11. What television sources of information on breast cancer are most <u>important</u> to you? Please rank the top three television sources you checked in question #II 10 above in order of importance, with 1 being the source of information that is most important to you, 2 the next most important. **(If you checked less than three sources, rank only those checked.)**

1_____
2_____
3_____

II 12. What television sources of information on breast cancer are most <u>trustworthy</u> to you? Please rank the top three television sources you checked in question #II 10 in order of trustworthiness, with 1 being most trustworthy and 3 being least trustworthy. **(If you checked less than three sources, rank only those checked.)**

1_____
2_____
3_____

II 13. In general, how confident are you that the information you hear about breast cancer on television is accurate?
____ not at all confident that the information is accurate
____ more unconfident than confident that the information is accurate
____ neutral; neither confident nor unconfident that the information is accurate
____ more confident than unconfident that the information is accurate
____ extremely confident that the information is accurate

Section III. Other Sources of Information About Breast Cancer.

III 1. From what sources have you received information about breast cancer besides the news or popular media sources indicated in the previous sections **(check all that apply)**?

___ personal physician
___ physicians in general
___ other health professionals
___ friends
___ relatives
___ books
___ scientific journals
___ campus organization
___ Internet
___ other (please specify)_____
___ I have never received information about breast cancer from other sources.
(If never, skip to section IV.)

III 2. Which sources of information about breast cancer other than the mass media are the most important to you? Please rank the top three sources you checked in question #III 1 in order of importance, with 1 being most important to you, 2 being the next most important. **(If you checked less than three sources, rank only those you checked.)**

1_____
2_____
3_____

III 3. Which sources of information on breast cancer other than the mass media are the most trustworthy to you? Please rank the top three sources you checked in question III1 in order of trustworthiness, with 1 being most trustworthy, 2 being the next most trustworthy. **(If you checked less than three sources, rank only those you checked.)**

1_____
2_____
3_____

III 4. I have heard about the following topic(s) related to breast cancer from the source(s) checked in question #III 1 **(check all that apply):**
____ breast cancer of a celebrity
____ breast cancer of a person other than a celebrity
____ breast cancer screening recommendations (age guidelines, recommended practices)
____ issues regarding effectiveness of breast cancer screening practices (mammography, clinical breast exams or self breast exams)
____ stories about women who had a gene that predisposed them to breast cancer
____ statistics about how often genes cause breast cancer
____ stories about how genes play a role in breast cancer
____ environmental factors related to breast cancer
____ other topic (please specify)_____

III 5. In general, how confident are you that the information you hear about breast cancer from these other sources is accurate?
____ not at all confident that the information is accurate
____ more unconfident than confident that the information is accurate
____ neutral; neither confident nor unconfident that the information is accurate
____ more confident than unconfident that the information is accurate
____ extremely confident that the information is accurate

Section IV. Family Communication About Breast Cancer.
IV 1. On average, I discuss issues related to breast cancer with the family member participating in this study with me:
____ never **(If never, skip to question #IV 6)**
____ one or two times total
____ one or two times a year
____ one time a month
____ one time a week
____ every day

IV 2. I have discussed the following topic(s) related to breast cancer with the family member participating in this study with me **(check all that apply):**
____ breast cancer of a family member
____ breast cancer of a friend
____ breast cancer of a celebrity
____ breast cancer screening (mammograms, clinical exams, self exams)
____ genetic factors related to breast cancer
____ environmental factors related to breast cancer
____ other topic (please specify)_____

Relatives of male students: skip to question #III 6

IV 3. I have recommended to the female family member participating in this study with me to conduct self-breast examinations:
___ have never recommended that she conduct breast self-examinations
___ daily
___ weekly
___ monthly
___ a few times a year
___ once a year or less

IV 4. I have recommended to the family member participating in this study with me to have a mammogram:
___ have never recommended that she have a mammogram
___ have recommended one time that she have a mammogram
___ once a year
___ once every two years
___ whenever recommended to her by her physician
___ other (please specify) _____

IV 5. I have recommended to the female family member participating in this study with me to have a clinical breast examination:
___ have never recommended that she have a clinical breast examination
___ have recommended one time that she have a clinical breast examination
___ once a year
___ once every two years
___ other (please specify) _____

IV 6. I feel that I am an influential source of information about health matters in general to the family member participating in this study with me.
___ strongly agree
___ somewhat agree
___ neutral
___ somewhat disagree
___ strongly disagree

IV 7. I feel comfortable talking about health matters in general with the family member participating in the study with me.
___ strongly agree
___ somewhat agree
___ neutral
___ somewhat disagree
___ strongly disagree

IV 8. Besides the family member participating in this study with me, I discuss health matters in general with the following family members **(check all that apply):**

___ I do not discuss health matters in general with other family members.
___ father
___ brother
___ sister
___ aunt or uncle
___ grandparent
___ son
___ daughter
___ spouse
___ other family member (please specify)_____

Students: skip to question #IV 11
Adult Female Relatives: continue with question # IV 9

IV 9. Has the student participating in this study with you ever given you printed information about breast cancer, such as a pamphlet, news article, or shower card **(Check all that apply)**?

____ No, never **(If never, skip to section V)**
____ Yes, information on breast self-examination instruction (such as a shower card)
____ Yes, information on screening guidelines
____ Yes, information on how to obtain a mammogram
____ Yes, story about a woman who had a gene that predisposed her to breast cancer
____ Yes, statistics about how often genes cause breast cancer
____ Yes, information about how genes play a role in the development of breast cancer
____ Yes, information on fund-raising events such as walks or races
____ Yes, other information (please specify) _____
____ Yes, cannot remember the specific type of information

IV 10. If you answered yes to question III9, what were the source(s) of the information she or he has given you? **(Check all that apply; after responding to this question, skip to section V)**

____ campus organization (i.e., sorority or fraternity)
____ university health center
____ newspaper or magazine article
____ other organization, such as the American Cancer Society
____ other (please list)_____
____ cannot remember the source of the information

IV 11. Have you ever given printed information about breast cancer, such as a pamphlet, news article, or shower card, to the adult female relative participating in this study with you **(check all that apply)**?

____ No, never **(If never, skip to section V)**
____ Yes, information on breast self-examination instruction (such as a shower card)
____ Yes, information on screening guidelines
____ Yes, information on how to obtain a mammogram
____ Yes, information on genetic factors related to breast cancer
____ Yes, information on fund-raising events such as walks or races
____ Yes, other information (please specify)_____
____ Yes, cannot remember the specific type of information

IV 12. If you answered yes to question #IV 11, what were the source(s) of the information you gave her (check all that apply)?

____ campus organization (i.e., sorority or fraternity)
____ university health center
____ newspaper or magazine article
____ other organization, such as the American Cancer Society
____ other (please specify)_____
____ cannot remember the source of the information

Section V. Behaviors.
Male participants: skip this section; continue to section VI.

V 1. Do you perform breast self-examinations? If so, how often?
___ do not perform breast self-examinations
___ daily
___ weekly
___ monthly
___ a few times a year
___ once a year or less

V 2. Do you have mammograms? If so, how often?
___ have never had a mammogram
___ have only had one mammogram
___ once a year
___ once every two years
___ whenever recommended to me by my physician
___ other (please specify) _____

V 3. Do you have physical examinations of your breasts performed by a health practitioner (clinical breast examination)?
___ have never had a clinical breast examination
___ have only had one clinical breast examination
___ once a year
___ once every two years
___ other (please specify) _____

V 4. Have you had any other kind of screening test on your breast(s) other than a clinical breast exam or mammogram?
___ no
___ yes (please specify)_____

Section VI. Personal Factors.
VI 1. Have you ever been diagnosed with breast cancer?
_____ yes
_____ no **(If no, skip to question #VI 6)**

VI 2. If yes, in what year were you diagnosed with breast cancer?

_____

VI 3. How old were you when you were diagnosed with breast cancer?

_____

VI 4. What type of breast cancer did you or do you have?

diagnosis _____
one or both breasts? _____

VI 5. Are you currently undergoing treatment for breast cancer?
____ yes
____ no

VI 6. Have you ever been diagnosed with a breast problem or disease other than breast cancer?
_____ no
_____ yes (please specify)
_____

VI 7. Have you ever had a test on your own genetic make-up? (e.g., a blood test to determine if you have a gene associated with blood clotting; a test for a gene linked to breast cancer)
_____ yes
_____ no **(If no, skip to question #VI 9)**

VI 8. For what condition(s) have you received genetic testing?

_____

VI 9. Have you ever had a prenatal (before giving birth) genetic test, such as amniocentesis?
_____ yes
_____ no

VI 10. Have you ever received genetic counseling for a disease or condition that has been found to run in your family? **(If no, skip to question #VI 12)**
____ yes
____ no

VI 11. If yes, please list the disease(s) or condition(s) for which you received counseling.

_____

VI 12. Have any women in your family (other than yourself) ever been diagnosed with breast cancer? **(check all that apply)**
_____ No other woman in my family has been diagnosed with breast cancer.
_____ mother
_____ sister
_____ aunt, mother's side
_____ aunt, father's side
_____ grandmother, mother's side
_____ grandmother, father's side
_____ other (please specify)_____

VI 13. Do you know anyone personally, other than a family member, who has had breast cancer? **(check all that apply)**
_____ I don't know anyone else personally who has had breast cancer.
_____ close friend
_____ acquaintance
_____ coworker
_____ other (please specify) _____

Demographic Items
1. What is your age?
_____ years

2. What is your sex?
____ male
____ female

3. What is your race?
_____ African American/Black
_____ Asian/Pacific Islander
_____ Caucasian/White
_____ Hispanic/Spanish-speaking
_____ Native American
_____ Multiracial
_____ Other (please list)_____

(SURVEY CONTINUED ON THE FOLLOWING PAGE)

4. Your Name:_____
(Names are being collected for extra credit/matching purposes ONLY and will be kept confidential.)

STUDENTS: Your portion of the study is complete. Thank you for your participation!

ADULT FEMALE RELATIVES: Continue with question #5

5. Name of the student participating in this study with you:

_____

6. Please indicate your relationship to the student listed in #7:
____ mother
____ other (please specify):_____

7. Are you biologically related to the student listed above?
____ yes
____ no

8. How many children do you have?
_____ # children total
_____ # boys
_____ # girls

9. What is your highest grade completed in formal education?
_____ below high school
_____ high school diploma
_____ some college (no degree awarded)
_____ 2-year college degree
_____ 4-year college degree
_____ some post-graduate (no degree awarded)
_____ graduate degree

10. What is your total annual household income?
_____ less than $25,000
_____ $25,001-39,999
_____ $40,000-59,999
_____ $60,000-79,999
_____ $80,000-99,999
_____ $100,000 or higher

11. If you would like a copy of the survey results mailed to you, please provide your mailing address below.

THANK YOU FOR YOUR PARTICIPATION.