

**MAMMOGRAPHY AND BREAST CANCER
MOTIVATIONAL MESSAGES:**

**A FOCUS GROUP STUDY OF THEIR
EFFECTIVENESS ACROSS ETHNIC GROUPS**

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1. EXECUTIVE SUMMARY

1.1 INTRODUCTION AND METHODOLOGY

The National Breast Cancer Education Program (NBCEP) was established by the National Cancer Institute's (NCI) Office of Communications (OC) to increase women's awareness of breast cancer and to encourage mammography screening. To fulfill program objectives, NCI strives to develop messages that convey the importance of regular screening to women ages 40 and older. An important part of this effort is designing messages that are meaningful and appealing to women across different ethnic groups as well as to women ages 65 and older.¹

During August 1999, OC conducted a series of focus groups with women of diverse ethnic backgrounds. The overall purpose of the research was to find out whether there are particular mammography and breast cancer motivational messages that resonate across ethnic groups, as opposed to having appeal only to a single group. The specific objectives of this research were:

- **To better understand African American, American Indian, Asian American, Caucasian, Latina, and older women's knowledge, attitudes, and behaviors regarding breast cancer and mammography;**
- **To assess reactions to motivational messages encouraging women to get mammograms; and**
- **To examine similarities and differences among ethnic groups, mostly in terms of message preference, but also with respect to knowledge, attitudes, and behaviors.**

Fourteen groups were conducted in three locations—New York City, Richmond (Virginia), and Los Angeles. Women ages 40 to 60, recruited primarily from lower to middle levels of the socioeconomic scale, were grouped by ethnic background: four groups with Latina women and two groups each with African American, American Indian, Asian American, and Caucasian women. Two additional groups were composed of older women (ages 65 to 75) whose ethnic background was African American, Caucasian, and Latina. Participants were excluded if they or any member of their household either currently or previously had cancer. Each group had between five and nine participants.

Focus group discussion centered around the testing of motivational messages pertaining to mammography. In all groups, the structure of the discussion was the same. First, the moderator asked participants to respond to a basic informational message which conveyed NCI's screening mammography guideline: *Starting at age 40, all women should have a mammogram every one to two years.* Next, the moderator introduced 10 messages designed to motivate women to get regular mammograms. Each participant was asked to select the motivational message they

¹ OC is collaborating with the Health Care Financing Administration (HCFA) to increase awareness of mammography screening and Medicare coverage for women ages 65 and older.

found most and least persuasive. Then the moderator led the group in a more detailed discussion of each message's strengths and weaknesses. The 10 messages were:

1. *Mammograms detect breast cancer long before a lump can be felt. And finding it early can save your life.*
2. *Mammograms detect breast cancer long before a lump can be felt. And finding it early can save your life so you can be there for your loved ones. (Alternative to #1)*
3. *Breast cancer can develop at any time.*
4. *Just because a woman hasn't gotten breast cancer by age 65 doesn't mean she won't get it. In fact, her chance of getting breast cancer increases as she gets older. (Presented only to the two older groups)*
5. *Just because you haven't gotten breast cancer by age 65 doesn't mean you won't get it. In fact, your chance of getting breast cancer increases as you get older. (Alternative to #4, presented only to the two older groups)*
6. *If you're afraid of finding out you have breast cancer, getting a mammogram may give you peace of mind.*
7. *If you're concerned about getting breast cancer, getting a mammogram may give you peace of mind. (Alternative to #6)*
8. *Each and every woman age 40 or older is at risk for breast cancer, even if no one in her family has ever had it.*
9. *As a woman grows older, her chance of getting breast cancer increases.*
10. *As you grow older, your chance of getting breast cancer increases. (Alternative to #9)*

Throughout the discussions, the moderator explored participants' knowledge, attitudes, and behaviors concerning breast cancer and mammography, sometimes probing underlying motivations and barriers. Toward the end of the session, each group was asked to respond to a makeshift, composite public service announcement (PSA) composed of the basic informational message, the most persuasive motivational message selected by that group, and a call to action featuring NCI's toll-free information line (1-800-4-CANCER). Finally, participants were shown a prototype brochure on mammograms and asked to comment on its "look."

OC videotaped and transcribed all focus groups. This executive summary reports the highlights of the analysis based on the transcripts.

1.2 CONTEXT FOR UNDERSTANDING MAMMOGRAPHY MESSAGES

Respondents reacted to messages and underlying concepts based on what they brought to the focus groups: their prior knowledge of breast cancer and mammography; their attitudes predisposing them to certain views; their behaviors that both reflect and reinforce their knowledge and attitudes; their motivations to get a mammogram and learn more about breast

cancer; and the barriers that set limits to what they can do, expect and perceive concerning mammography screening.

Knowledge and Information Sources

- **Participants demonstrated a basic knowledge of recommended mammography screening behavior.** The vast majority understood that they should get regular mammograms, and that doing so would check for early signs of breast cancer. A high proportion of women in each group also indicated a knowledge and practice of breast self-examination (BSE).
- **Older women knew that Medicare helps pay the cost of regular mammograms for Medicare recipients.**
- **Most participants found personal experience, or experience gleaned from others, to be the most compelling source of knowledge about breast cancer and mammography.**
- **The advice of a doctor was another major knowledge source.** At least one person in every focus group emphasized their principal reliance on their doctor for information and advice on breast cancer and mammography. When personal knowledge or experience seemed to conflict with a doctor's recommendation, most participants deferred to the doctor's authority. Other sources of knowledge nearly always lost out when in perceived conflict with either the advice of a doctor or a participant's personal experience.
- **Participants expressed a willingness to consult a wide range of materials and sources to learn more about breast cancer and mammography.** Many participants said they would turn to print and broadcast materials, the Internet, social services, clinics and hospitals, and other public or official places such as the workplace, tribal networks, pharmacies, and community centers.

Attitudes

- **The proactive attitude exhibited by many women toward health was striking.** Participants in all groups repeatedly discussed ways in which they actively embrace information pertaining to their health. All groups included some women who reported a commitment to maintaining a healthy diet and being physically active.
- **A commonly-held belief was that breast cancer can strike anyone.** The majority of participants believed this was true regardless of age, with a handful mentioning it was also true with respect to other characteristics such as gender, socioeconomic status, and ethnicity. This attitude of universal risk led many participants to accept messages whose wording emphasized the importance of regular screening for all women, not just women age 40 and over.
- **Many participants also displayed a skeptical attitude toward mammograms, voicing concern about their accuracy.** Often this skepticism was expressed through anecdotal stories whose implicit lesson was that mammograms are not always reliable.

- **Participants exhibited a fundamental deference to the authority of doctors.** This attitude varied by group and was sometimes complicated by undercurrents of skepticism and uncertainty about the accuracy of mammograms and recommended screening guidelines.

Mammography Behaviors and Motivators

- **Women in all groups reported a high degree of compliance with the behavior encouraged by the basic informational message on mammography.** Nearly every participant had received a mammogram, and many said that they did so on a regular basis.
- **Participants most often stated that they got mammograms to ensure a high quality of life—to remain healthy and independent, to feel young and happy, to enjoy life, and to avoid pain.**
- **Closely related to quality of life was the motivation to stay healthy for one’s family.** Nearly all women made at least some reference to their family when discussing the reasons why they got regular mammograms.
- **Nearly as compelling as the desire to maintain a high quality of life and to stay healthy for the family was the willingness to follow a doctor’s instructions.** Women often stated that they got mammograms because their doctor told them to.
- **Despite the primacy of the family, there was a tension between being healthy for the family and looking out for oneself.** Some women were able to resolve this tension by claiming that the two motives were one and the same, since their families were their greatest source of personal happiness.

Barriers

- **When asked about barriers that might prevent women from getting a mammogram, participants most frequently mentioned money as a factor.** High fees and inadequate insurance coverage were considered to be the most likely obstacles to screening.
- **Despite the perceived barrier of cost, however, participants in all groups said they were able to get mammograms one way or another—if not through insurance or Medicare, then at clinics, hospitals, community centers, or through some other free avenue.** Participants in every demographic category said they knew that either their own health insurance or Medicare provides free screening for its enrollees, and indicated that this knowledge motivated them to get a mammogram.
- **Some participants mentioned fear as a barrier,** stressing that young women or women fearing a positive cancer test result might be too apprehensive or “stubborn” to practice recommended screening behavior.
- **Participants noted that the physical experience of the mammogram procedure was unpleasant.** The pain and discomfort caused by mammograms was mentioned often and insistently.

1.3 RESPONSES TO THE BASIC INFORMATIONAL MESSAGE

The first message tested by moderators in all focus groups was a basic informational message:

Starting at age 40, all women should have a mammogram every one to two years.

Women in all focus groups responded favorably to this message, finding it clear and informative, perhaps because many were already somewhat familiar with the screening guideline. Beneath the surface of this approval, however, were some crosscurrents that limited the effectiveness of this and the other tested messages.

- **Confusion about age as a risk factor.** Despite a widespread understanding that women should get mammograms, participants in all groups expressed confusion about the basic facts of breast cancer risk, mammograms, and mammography screening. The most commonly expressed objection to the basic informational message, heard most frequently in the Caucasian groups, was that women should get screening mammograms before age 40.
- **Preference for inclusive language.** Partly because of the confusion about age as a risk factor, many participants responded positively to the part of the basic informational message that stated “all women should have a mammogram.” The prescriptive quality of this phrase also appealed to some women who placed a high value on personal health and prevention.
- **Anecdotal experience as a benchmark.** Participants were constantly testing messages against their personal experience, which they considered more authoritative than nearly all sources of information other than a doctor’s advice. Group discussion was often influenced by personal testimonials in which women shared stories they perceived as contradictory to the basic informational message.
- **Skepticism about the accuracy of mammograms.** The message underlying many of the participants’ personal stories was that mammograms might not be completely reliable. However, such skepticism should be interpreted alongside the nearly universal assertion among participants that they had regular mammograms.

1.4 RESPONSES TO TEN MOTIVATIONAL MESSAGES

When the votes were tallied across groups, it was clear that participants considered one message most persuasive and another least persuasive, while the remaining messages elicited more neutral responses. Despite these aggregate trends, the presence of some variation between groups makes generalization about relative persuasiveness difficult for any of the messages, except the one judged least persuasive. Consequently, responses to motivational messages are discussed separately.

- **Most persuasive message: “Mammograms detect breast cancer long before a lump can be felt. And finding it early can save your life.”** This message appealed to participants in all groups, surpassing all other messages. However, the aggregate popularity of this message

conceals some variation among supporters. It received strong support in certain ethnic groups—in all Latina groups and, with more mixed reaction, in African American and American Indian groups. The most commonly stated reason for choosing this as the most persuasive message was that it is positive and gives hope. The phrase “it can save your life” was singled out as particularly appealing because of its hopeful ring. But, this message did not stand out for older, Caucasian, and Asian American women, who most commonly stated that this message could be misleading given their belief that mammograms are not always 100% foolproof.

- **Second-most persuasive message: “Breast cancer can develop at any time.”** Many participants liked this message because of its simplicity and directness, finding it both clear and credible. Those who disliked the message often gave the same reason for their response that supporters gave—simplicity—complaining that it had “no message” due to its shortness and vagueness.
- **Message targeted to older women: “Just because a woman hasn't gotten breast cancer by age 65 doesn't mean she won't get it. In fact, her chance of getting breast cancer increases as she gets older.”** Most participants in the two groups of older women felt that this message was correct and important, even if it was something they already knew. Because this message was deemed accurate and clear, the alternative version -- phrasing the message in the second person -- was not considered a good idea.
- **Least persuasive message: “If you're afraid of finding out you have breast cancer, getting a mammogram may give you peace of mind.”** The negative response to this message was unmistakable. It was the message most frequently identified as least persuasive. But more striking than the pattern of votes for least persuasive was the intensity with which participants expressed their dislike for this message because of its use of the word “afraid.” Also bothersome to many participants was the suggestion that they might overcome being afraid of breast cancer by getting a mammogram.
- **Less persuasive message: “Each and every woman age 40 or older is at risk for breast cancer, even if no one in her family has ever had it.”** This message received mixed and mildly negative reactions. The strongest objection was to the specification of age 40 as a point of demarcation, which some considered arbitrary due to their confusion regarding age as a risk factor. A number of participants liked the last portion of the message because it seemed to support their uncertainty about the concept of risk factors and their related conviction that anyone can get cancer.
- **Less persuasive message: “As a woman grows older, her chance of getting breast cancer increases.”** The main reason given for disliking this message was the explicit reference to women aging. Participants in every demographic category except older women were uncomfortable with this use of the word “older.” Participants often said that they did not know age was a risk factor for breast cancer, explaining the frequent comments that older women should not be singled out in such a message. The alternative to this message, which used the second person instead of the third, was even less popular, as most participants agreed that it was a bad idea to personalize a message that was already deemed unappealing.

1.5 RESPONSES TO 1-800-4-CANCER AND MAMMOGRAPHY BROCHURE

In addition to the basic informational message and 10 motivational messages, moderators tested a makeshift, composite PSA that combined the basic informational message, the most popular motivational message selected by each group, and a call to action featuring NCI's toll-free information line, 1-800-4-CANCER. Moderators also tested the general "look" of a proposed NCI brochure on mammography to see if the visual image was appealing.

- **Public Service Announcement (PSA).** The consensus in most groups was that the PSA would motivate them to call 1-800-4-CANCER to learn more about breast cancer and mammography. Many indicated that they would only use the 800 number if it connected them to a "live person" who could respond to their personal concerns. Adding a reference to the National Cancer Institute made the PSA more authoritative and persuasive according to most participants.
- **Brochure.** The overall response to the brochure's appearance was positive. Opinions were divided on whether photographs or artwork were preferable, but one thing seemed to be clear in all groups: images featuring ethnic diversity and multiple generations of women would make the brochure even more relevant and appealing.

1.6 CONCLUSIONS

- **Women have a proactive stance toward health but only a basic level of knowledge about mammography and breast cancer.** Women actively embrace information pertaining to their health. However, while the vast majority understand that they should get regular mammograms and that doing so checks for early signs of breast cancer, many say they are confused by inconsistent messages and guidelines related to when to begin mammography screening and to subsequent screening frequency. Many are also skeptical about the effectiveness of mammography and the competence of mammography technicians.
- **Messages should tell women why they should get regular mammograms and not explicitly focus on fear or age.** The most effective motivational messages tested had a tone that was informative and hopeful, and included the following informational elements: breast cancer can develop at any time; all women are at risk (even those age 65 and older, or those without a family history); mammograms can detect breast cancer early; and early detection can save lives. The least persuasive messages made explicit references to issues that were considered turnoffs—namely, fear, getting older, and the seeming illogic of using age 40 as a cutoff, given the value of early detection.
- **A doctor's authority and personal experience, including knowledge of other women's experiences, are the most trusted sources of health information, despite some uncertainty and questioning.** Women turn to many sources of knowledge (e.g., personal, friends', and family experiences; hearsay; folk wisdom; "alternative" medicines) to supplement what they learn at the doctor's office. In the end, however, they rely on their doctors for "the final word" on health advice.

- **Women are not lacking in exposure to communication channels.** A broad range of communication channels (e.g., print, broadcast, Internet, clinics, hospitals) were mentioned as sources of trustworthy information on breast cancer and mammography.

1.7 RECOMMENDATIONS

Overall findings indicate that none of the motivational messages tested in this study would be effective, in their current form, for use in a campaign to reach women across different ethnic groups. However, certain message elements resonated well with participants and should be incorporated into a new message that will expand the basic knowledge women already have about mammography and breast cancer, as well as convey both information and hope. These message elements are:

- Breast cancer can develop at any time [informational message]
- All women are at risk – even those age 65 and older, or those without a family history [informational message]
- Mammograms can detect breast cancer early [message also conveying hope]
- Early detection can save lives [message also conveying hope]

In creating a new message (e.g., PSA), it will also be important to make sure that the elements that are combined are not in conflict with each other or with the science of mammography screening. Some participants in the focus groups, for example, noted that the messages *Breast cancer can develop at any time* and *Early detection can save lives* are in conflict with the basic informational message, *Starting at age 40 all women should have a mammogram every one to two years*. Why, they questioned, should a woman wait until age 40 to begin having mammograms if breast cancer can develop at any time and early detection saves lives?

The following additional recommendations related to message design should also be considered based on their commonality across groups:

- **Personalize messages.** Consider framing a message in the form of an intimate personal story. Keep in mind, however, that messages which get “too personal,” such as those touching on deep fears about cancer, may backfire, especially if they include directive words such as “you” or “your.”
- **Call upon a doctor’s authority.** Include the figure of a doctor in the visual component of the message. Most women want knowledge from an expert, although a caring expert is most appealing. Images of female doctors may be less threatening than those of male doctors.
- **Evoke fear but do not name it.** Do not mention fear of cancer in the message or use “scare tactics.” Rather, allude to breast cancer gently in the context of the knowledge and reassurance that mammography can provide.

- **Involve family but do not preach.** Use the image of a happy and healthy family as a motivator for health-seeking behavior, since women in all groups mentioned their family as a major reason for staying healthy. However, avoid didactic or morally tinged statements, since some women resented being told explicitly that they ought to have a mammogram in order to “be there for their family.”
- **Use testimonials from "ordinary" people who are cancer survivors.** If a female celebrity is included, she should be a breast cancer survivor and should appear in public events and present PSAs alongside "everyday" women who also survived breast cancer. Testimonials from "ordinary" people providing facts and statistics would be both persuasive and educational.
- **Explain the significance of age 40.** Messages targeting women ages 40 and older must give an explicit rationale for using this age demarcation. Too many women were confused or skeptical about this dividing point to leave it implicit or unexplained.
- **Clarify the risk factor of aging.** The cumulative effect of aging as a risk factor was lost on many women who focused only on the notion of age, or the word “older,” both of which had negative connotations inconsistent with their self-image.
- **Pay close attention to language.** Consider each word in a message carefully. Substituting just one word in a message with another was often enough to entirely change most participants’ reaction to the message. Words such as “afraid,” “older,” “cancer,” “risk” and “should” were highly charged; this was also true for Spanish words such as protuberance or lump (“protuberancia”), chest (“pecho”), and mammogram (“mamograma”).

2. BACKGROUND AND METHODOLOGY

2.1 INTRODUCTION

The National Breast Cancer Education Program (NBCEP) was established by the National Cancer Institute's (NCI) Office of Communications (OC) to increase women's awareness of breast cancer and to encourage mammography screening. To fulfill program objectives, NCI strives to develop messages that convey the importance of regular screening to women ages 40 and older. An important part of this effort is designing messages that are meaningful and appealing to women across different ethnic groups as well as to women ages 65 and older.²

During August 1999, OC conducted a series of focus groups with women of diverse ethnic backgrounds. The overall purpose of the research was to find out whether there are particular mammography and breast cancer motivational messages that resonate across ethnic groups, as opposed to having appeal only to a single group. The specific objectives of the research were:

- **To better understand African American, American Indian, Asian American, Caucasian, Latina, and older women's knowledge, attitudes, and behaviors regarding breast cancer and mammography;**
- **To assess reactions to motivational messages encouraging women to get mammograms; and**
- **To examine similarities and differences among ethnic groups, mostly in terms of message preference, but also with respect to knowledge, attitudes, and behaviors.**

2.2 FOCUS GROUP DESIGN

2.2.1 Group Composition

A total of 14 focus groups were conducted in three locations – New York City, Richmond (Virginia), and Los Angeles. Twelve of these groups were conducted with women ages 40 to 60: four groups with Latina women and two groups each with African American, American Indian, Asian American, and Caucasian women. In addition, two groups were conducted with older women ages 65 to 75; these groups were of mixed ethnicity, including African Americans, Caucasians, and Latinas.

The table below summarizes the location and composition of the groups:

² OC is collaborating with the Health Care Financing Administration (HCFA) to increase awareness of mammography screening and Medicare coverage for women ages 65 and older.

New York, NY	Richmond, VA	Los Angeles, CA
Latinas 40-60 (2 groups)	Older women 65-75	American Indians 40-60 (2 groups)
	Caucasians 40-60 (2 groups)	Latinas 40-60 (2 groups)
	African Americans (2 groups)	Asian Americans 40-60 (2 groups)
		Older women 65-75

The American Indian groups contained a mix of tribes (e.g., Apache, Chippewa, Creek, Los Coyotes, San Manuel, San Ysabel, Shumach, Sious, and Soboba), and the Asian American groups contained a mix of Chinese, Japanese, Korean, Vietnamese, and Filipino women. The New York Latina groups were composed of Cuban, Dominican, and Puerto Rican women, while those in Los Angeles consisted of Mexican and Central American women. To be eligible for the focus groups, potential participants had to have lived in the United States for at least four years.

Each group included five to nine participants and, except for the Caucasian and mixed older groups, was led by a moderator having the same ethnic background as the participants.³ The Latina groups were conducted in Spanish, while all others were in English. The recruitment screener was designed to recruit women primarily from lower to middle levels of the socioeconomic scale. Participants were excluded if they or any member of their household currently or previously had cancer, or if they had ever worked in a medical, health care, or marketing setting. Each group was approximately two hours in length. All groups were audiotaped and videotaped. (See Appendix A for Participant Recruitment Screeners.)

2.2.2 Content of Discussion

The discussion or moderator’s guide was developed to test a set of 10 motivational messages on mammography, as well as to examine women’s knowledge, attitudes, and behaviors concerning breast cancer and mammography.

The discussion began with introductions and some general warm-up questions regarding the importance of health and participants’ current health care practices. After eliciting what participants already knew about mammograms, the moderator presented a poster board containing NCI’s basic informational message: *Starting at age 40, all women should have a mammogram every one to two years.* Participants then discussed their reactions to this message, including any information that was new to them.

Following the basic informational message, participants were shown 10 motivational messages that summarized reasons why women should get regular mammograms. Each message was

³ The Caucasian and mixed older groups were conducted by a moderator originally from India.

written on a separate poster board and displayed around the room. Participants were asked to jot down on a piece of paper the message that grabbed their attention most, and the message that grabbed their attention least. After the moderator tallied the responses to each message by a show of hands, the messages were discussed individually to identify their strengths and weaknesses. The 10 messages are presented below:⁴

1. *Mammograms detect breast cancer long before a lump can be felt. And finding it early can save your life.*
2. *Mammograms detect breast cancer long before a lump can be felt. And finding it early can save your life so you can be there for your loved ones. (Alternative to #1)*
3. *Breast cancer can develop at any time.*
4. *Just because a woman hasn't gotten breast cancer by age 65 doesn't mean she won't get it. In fact, her chance of getting breast cancer increases as she gets older. (Presented only in the older groups)*
5. *Just because you haven't gotten breast cancer by age 65 doesn't mean you won't get it. In fact, your chance of getting breast cancer increases as you get older. (Alternative to #4, presented only in the older groups)*
6. *If you're afraid of finding out you have breast cancer, getting a mammogram may give you peace of mind.*
7. *If you're concerned about getting breast cancer, getting a mammogram may give you peace of mind. (Alternative to #6)*
8. *Each and every woman age 40 or older is at risk for breast cancer, even if no one in her family has ever had it.*
9. *As a woman grows older, her chance of getting breast cancer increases.*
10. *As you grow older, your chance of getting breast cancer increases. (Alternative to #9)*

Following the discussion of the motivational messages, the moderator's questions shifted to participants' knowledge, attitudes, and behaviors concerning breast cancer and mammography. Specific questions addressed participants' perceived risk of breast cancer, breast cancer prevention practices, methods of paying for mammograms, knowledge of Medicare coverage of mammography, and resources for mammography information and advice.

Toward the end of the session, participants in each group were asked to react to a makeshift, composite public service announcement (PSA) created by combining the basic informational message (discussed above), the most popular motivational message in that group, and a call to action featuring NCI's toll-free line operated by the Cancer Information Service. The call to action read: "Call 1-800-4-CANCER. Cancer information from people who care." Discussion focused on reactions to the 1-800 number and the National Cancer Institute as the PSA sponsor.

⁴ Several messages are labeled as "alternative" messages. These are essentially the same as the messages they follow except they are rephrased in the second person to personalize them or they substitute one word with another.

Finally, participants were shown a prototype brochure on mammography and asked to comment on its “look.” (See Appendix B for Focus Group Moderator’s Discussion Guide and Appendix E for a copy of the brochure -- "Mammograms: Not just once, but for a lifetime", NIH Publication No. 97-3418.)

2.2.3 Analysis

Transcripts were prepared from all the audiotapes and then analyzed as a basis for synthesizing the findings and formulating the generalizations found in this report. A detailed description of the rationale and procedures used for analyzing the data can be found in Appendix C (Note on Method of Analysis).

It is important to note that qualitative research of this sort is highly instructive for developing communication messages and strategy because it provides rich, in-depth information that is useful in understanding what and how people think, feel, and behave. However, because participants are not independent random samples and the data take the form of group conversations rather than answers to identically administered questionnaires, the data are not statistically generalizable to any population. This study is further limited by the fact that different moderators were used for different ethnic groups.

3. DETAILED FINDINGS

3.1 CONTEXT FOR UNDERSTANDING REACTIONS TO MAMMOGRAPHY MESSAGES

Women's responses to the tested mammography messages were shaped by their life circumstances. Respondents reacted to messages and underlying concepts based on what they brought to the focus groups: knowledge of breast cancer and mammography based on experience, exposure to media, and the advice of their doctors; attitudes toward breast cancer and mammography that predisposed them toward certain views regardless of evidence or messages; behaviors that reflected and reinforced their knowledge and attitudes; motivations to guard their health that gave meaning and direction to their mammography-related perceptions and practices; and barriers that set limits to what they could do, expect and perceive concerning mammography screening.

3.1.1 Knowledge

Participants demonstrated a basic knowledge of the need for mammography. "Basic knowledge" for the majority of these women meant that they understood they should get regular mammograms and that doing so would check for early signs of breast cancer. This understanding of the *purpose* of mammography helps to explain the success of the basic informational message (see section 3.2 below).

"What I'm trying to say is that even if a lump pops up in between mammograms, you're still catching it early because you know that lump has come up since your most recent mammogram, so that's still very early." (Caucasian)

"The thing about finding a lump before you feel it. In the test, it can come out much faster." (Latina)

"And the purpose for the mammogram is to catch it while it is small. And, therefore, once every year or two should be sufficient to see if there is a growth or if there's some change that every six months you may not see a sufficient change." (African American)

"A mammogram doesn't prevent..it just tells you whether you have it or not." (African American)

"A mammogram is very important if you were to go and get it because you can find out whether you have cancer..the earlier it's discovered, the more easy to do something about it." (Older)

Participants' knowledge, however, encompassed mainly the need for screening and too often did not include an informed perspective on breast cancer risk or recommended screening practice. Beneath the surface of participants' knowledge were some variations and gaps in actual understanding. For example, there was considerable uncertainty about the timing and frequency of the recommended screening procedure for mammography. Women in three focus groups—one African American, one American Indian, and one Asian American—went to considerable lengths to express concern that women should

have mammograms earlier in their lives than age 40, and more frequently than every one to two years. (See section 3.2 below.) Although every demographic group except older women claimed, at least once, to understand some of the risk factors associated with breast cancer, there was some confusion about increased risk with age. For example, a participant in one American Indian group said, "Does that mean that you have to wait until you're 40 before you have a lump found? That it's going to save your life then?"

Although rare, a few women expressed beliefs that reflected how misinformed they were about breast cancer and mammography. One recurring misconception was that a blow to the breast could cause cancer—a confusion that, in at least one case, led a woman to conclude that the pressure exerted on the breast during a mammogram was in itself a cancer risk. Other misconceptions reflected a basic lack of knowledge about cancer.

"I think when you fall or hurt yourself, when you hit yourself, maybe you might not think you've gotten hurt, but maybe you can get cancer because of these blows." (Latina)

"If you've been hit or knocked down and punched and such, I think that could [put] a person at higher risk." (Older)

"And you wonder when they're actually putting your breast in and putting you in all kinds of ways that they're not hurting the tissues themselves, and actually bruising you if you did have any cancer cells in there, that they're actually making them spread." (American Indian)

"I think they say we all have these diseases; it's just a matter of whether they have developed." (Latina, LA)

"Women nurse their children, and children eat food and if the children eat and then they nurse without washing their mouths, maybe the mothers can contract some kind of disease." (Latina)

"I read something about, and I can't remember all of it, but it said we all have cancer cells in our bodies. It depends on what triggers them to start activation." (Caucasian)

Most participants found personal experience, along with information gleaned from friends and family, to be the most compelling source of knowledge about breast cancer and mammography. Each focus group featured at least one personal recollection, and often the discussions turned into exchanges of these stories. Experiences recounted by friends and family were easy to grasp and held deep personal significance for participants—sometimes to the detriment of other information sources that seemed to contradict this experience. For some women, anecdotal stories were their primary source of information regarding breast cancer and screening.

"I go [get a mammogram] every year because I have a cousin that never, never did a mammogram, and in a year [she] started to get a discharge, and she still does not go [to the doctor] ...they've taken one breast off, and she's got cancer now in her lungs. And for me that's something; how can this be, that she wasn't aware of this? If she had all of these symptoms, and she never went [to the doctor] and now it's too late." (Latina)

"At my work my boss had a mastectomy, and she had a terrible case of cancer. We watched her from the moment she found out she had cancer. As soon as we found out about this sickness, all of the ladies went to have a mammogram." (Latina)

"[To motivate women] I would tell them about my husband. It is not breast cancer, but he had lung cancer. The year before when he had his annual physical, it wasn't there. The next year it was there. And if he hadn't taken that, he'd probably be gone by now. . . And I would tell them about my aunt who didn't continue even after she found out she had breast cancer. She got to a point she was feeling so well she just stopped going. And then before we knew it, she was gone completely." (African American)

"My daughter had [the mammogram] done at 22 years old. My niece had her baby, and she went in at 32 years old and now she is gone. They did all these tests and it is just too late." (Older)

"You gotta have a mammogram because . . . my mother died of lung cancer . . . my friend died from bone cancer but it originated from breast cancer." (Asian American)

"I have a friend who just died from cancer, because she didn't catch it in time. She found out when she couldn't do anything for herself, and I want my health. I value my life, and that's why I go to the doctor every year." (Latina)

The advice of a doctor was another major knowledge source. At least one person in every focus group (and usually more than one) emphasized their primary reliance on their doctor for information and advice on breast cancer and mammography. When participants brought up anecdotal information which seemed to conflict with a doctor's recommendation, most participants deferred to the doctor's authority, acknowledging the contradiction by admitting that they might not have the medical background to fully understand the issue. This does not mean that participants trusted medical authority unconditionally. Many participants expressed skepticism about the public health messages they had encountered regarding breast cancer and mammography (see discussion of skepticism in section 3.1.2 below). However, their main reference points remained anecdotal information (about themselves and others) and the authority of the doctor, since skepticism provides little basis for preventive action in safeguarding one's personal health (a major motivation for most participants—see section 3.1.4).

"Well, it would depend on your doctor." (African American)

"The doctors convinced me a long time ago." (Older)

"I feel comfortable talking to my doctor. When I go in, we usually have this little conversation before she ever does an exam. And I think if I were having a problem, I would go talk to her." (Older)

"Because everything that will come out of [calling the 1-800 number] is 'go see your doctor'." (Asian American)

Other sources of knowledge nearly always lost out when in perceived conflict with either the advice of a doctor or the anecdotal experience of a participant; despite this tendency, however, participants expressed a willingness to consult a wide range of sources to learn more about breast cancer and mammography. These included:

- Broadcast media (television and radio programming) -- perhaps the most commonly mentioned source;
- Print media (magazines, newspapers) -- mentioned almost as frequently;

- Advertising (outdoor as well as print, television and radio) -- often mentioned and sometimes equated with the media in which it appeared;
- Print materials (books, brochures, medical journals) -- sought after by women in most focus groups;
- The Internet -- mentioned by some groups, although a large number of women emphasized that they did not use it as a source of information;
- Social services, charities, and churches -- mentioned often;
- Clinics and hospitals -- often identified as places where women would seek out information -- as were cancer societies, health fairs, and insurance companies;
- Public or semi-official places such as state governments, tribal networks, libraries, and senior citizen and community centers (e.g., YWCA) -- considered good places to look for information; and
- Commercial and other non-official public spaces such as dance centers, the workplace, pharmacies and supermarkets, malls, beauty and nail shops, and women's public bathrooms.

Women of different ages and ethnic backgrounds mentioned getting mammography and breast cancer information from different sources. Broadcast and major print media (television, radio, newspapers, magazines) figured prominently for at least one focus group in each demographic group, except for Asian American women, who mentioned these sources infrequently or not at all. Latina, African American, and older women mentioned their doctor and hospitals or clinics as information sources much more frequently than did participants in other groups. Latina, American Indian, and older women made a special point of emphasizing that they did not get their health information from the Internet.

3.1.2 Attitudes

Participants' attitudes toward health, breast cancer, and mammography screening played a large role in determining responses to specific messages and underlying message concepts such as risk. Participants who trusted their doctor's advice or took a proactive stance toward safeguarding their personal health often responded positively to messages that alienated others not wanting to be reminded of the risks and consequences of breast cancer.

The generally proactive stance toward health adopted by many women in all groups was striking. Participants repeatedly discussed ways in which they actively embrace information pertaining to their health. They also emphasized the high priority they place on doing whatever they can to improve their health.

"You want to be sure about your health. It's much better to scream beforehand than to groan afterwards." (Latina)

"Just the awareness that the possibility is there. I want to be the first to know it and not find out about it years down the road. So just precaution." (African American)

Participants exhibited a fundamental deference to the doctor's authority. This trust was probably the reason most women reported having regular checkups. Expressed trust in a doctor varied by group, however: Caucasian and American Indian women made far fewer references to this trust than did women in the other groups. Many women stated that certain symptoms, such as secretion from the nipple, enlarged lymph nodes, and/or a lump, pain, or inflammation in their breast(s) would be reason to visit their doctor immediately.

"If I have any comment or question, I talk to the doctor, because the nurse doesn't know." (Latina)

".when you find out that a friend or relative has a disease, you start running to have an appointment to make sure you don't have the disease. If we hear that someone died of something, then you go running to the doctor." (Latina)

"At some of the non-profits, they get some training but the end result is you need to go see your doctor. [At the non-profits], they are trained but they are not medically trained." (Asian American)

"Other than the self-exam, the doctor." (African American, responding to "Is there anything else you would do to check for breast cancer?")

"When I have an ache, I'll talk to the doctor." (American Indian)

One common attitude, though less apparent among Asian American women, was the belief that breast cancer can strike anyone. The majority of participants believed this was true regardless of age, leading some (later in the groups) to prefer messages whose wording emphasized the importance of regular screening for all women, not simply women age 40 and over (see section 3.2). A handful of participants mentioned this was also true with respect to other characteristics such as gender, socioeconomic status, and ethnicity.

"But I think they need to know that it can happen at any age because young women don't look for it. Young males, they don't look at it. And I have heard men get it." (Caucasian)

"Nobody is immune." (Caucasian)

"It's not that everybody is going to have it [breast cancer], but there is a risk there for everybody." (Caucasian)

Exchange between older participants:

"Cancer doesn't seem to evade anybody."

"That's true."

"You know, wealthy people, poor people."

"They ask men to go and take a mammogram."

"See a man has a chest ["pecho"] but a woman has breasts ["senos"] and men get breast cancer in the chest too." (Latina)

"Even men, men are getting breast cancer a lot." (American Indian)

Interestingly, the groups that most frequently asserted that cancer could happen to anyone – Caucasian – also made the most mention of family history as a risk factor.

"Based on what you said, your family history; I'm thinking maybe like she said at 18, 19, or 20. Especially both sides, mother and father. Like in my case, my daughter, she's 25, but both grandmothers had breast cancer. My mother was 45 when she was diagnosed with cancer and her other grandmother was 60. So she didn't really know either one of her grandmothers. So she's really prone to having cancer maybe so she should get a checkup and mammogram at 25." (Caucasian)

"On my father's side of the family, they were from Lebanon, and he died when I was 12 so I have no history in his side either. I have no knowledge of any family history so I wouldn't know whether it ran in the family or not." (Caucasian)

"I don't have [mammograms] yearly as they recommend because I don't think it is necessary for myself since I don't have a history of breast cancer. And I know it's not a guarantee, but still think I'm better off not having mammograms yearly." (Caucasian)

"If you've got a history, then earlier. I don't think it should be a blanket statement of any age." (Caucasian)

"My family history stinks. The females in my family don't live past 50. .If you have that baseline early on and you have these mammograms periodically..." (Caucasian)

Family history or genetics was generally perceived as a risk factor requiring proactive behavior in order to detect breast cancer earlier or lower one's risk. Asian Americans, in particular, tended to refer to family history, also placing a great deal of emphasis on the notion that lifestyle determines risk for breast cancer.

"No one's had cancer but those cysts or lumps or whatever tend to run in my family. We have lumpy breasts, so I had [a mammogram] as a benchmark." (Asian American)

"And then both my mom and dad are very old. I mean, my mom is 83, still going on. My father died when he was 86, so I just think I'm going to be okay." (Asian American)

"There are women who have had breast cancer in their family who go in and have their breasts removed without having had cancer, because they feel they are at risk." (Older)

"I've never read or heard of a thing that would tell me how to identify my [risk] unless it is in my family history." (African American)

"To me it would be family history. That is the main thing. I really don't feel that the environment has a great deal to do with it even though our environment keeps changing." (American Indian)

"I feel if it's prevalent in the family, perhaps they should start earlier and have [mammograms] more often." (Older)

"I feel I'm low risk simply because of my family history." (Older)

"I think I'm at very low risk because I don't smoke, I don't drink, unless, you know, at some birthday party or whatever, and I barely eat any canned food - mostly fresh - and my life is very simple. I don't have a party life, you know what I mean? .so I think I'm going to be okay." (Asian American)

"I think I'm at low risk because I don't smoke or drink." (Asian American)

Many participants exhibited a skeptical attitude toward mammograms, voicing doubts about their accuracy. Women of every demographic category except Latina devoted considerable time to spontaneously discussing and questioning the reliability of mammogram results. Often this questioning came out in the form of a personal story (especially among Caucasian women) whose moral was that you could never be too careful—even if you followed recommended mammography screening guidelines. Many discussions about specific motivational messages shifted into such stories, with skeptics using evidence from “real life” as testimonials against the message in question. A minority of skeptics directly questioned the expertise of technicians, but most simply told stories about false negative and positive results received by family members and friends. In the end, participants relied on the advice of their doctor and reported getting regular mammograms, but not without considerable questioning and comparison of medical advice against their personal experience.

"My sister went to have a mammogram and they told her that she had cancer, but she didn't have cancer. They did a biopsy, and there has been nothing. That was 20 years ago." (Latina)

"Yeah, that's what scares me. They [mammograms] are not always accurate. You see so many things on TV where even the machines are malfunctioning and the people who actually read the mammograms really don't know how to read them." (Caucasian)

"I have a very close friend, about five years ago had to have a mastectomy and she found the lump herself and she had just had a mammogram less than three months before and they found nothing." (Caucasian)

"I'd rather go to the same doctor for GYN and go different places for my mammogram. Because just like I said before, they had on the news that all those machines are not accredited. So, I don't take a chance on just one machine." (African American)

"They don't catch everything. Because when I went for my first [mammogram], I didn't ever want to go ever, and I said I will do it, and lo and behold, it came back something was wrong and they thought I had cancer. Right away I got upset, and so they had me go in the next week for the same thing, and so I waited for about a week, and they finally called me and they said everything was fine. So it did upset me, so now I'm deathly afraid of going back." (American Indian)

"I had a friend ..who went for a regular physical checkup including a mammogram, and it was normal. But when she was taking a shower, she kind of felt something at the very tip of the breast. And, so, she went to the doctor the next day and they gave another kind of mammogram, and they showed that it was cancerous. But the reason Kaiser told her that the first one was normal was because usually the mammogram doesn't show the tip part of the breast." (Asian American)

3.1.3 Behaviors

All groups included some women who reported a commitment to maintaining a healthy diet and being physically active. However, there were some variations to this overall tendency by ethnicity. African American and American Indian women mentioned diet less frequently than women in the other focus groups. Asian American women in one particular focus group devoted extensive commentary to the importance of a good diet in preventing cancer, again

reflecting a distinctive belief in the importance of behavior or lifestyle in determining breast cancer risk.

"In my house, I try to make sure that we are eating right. I want to make sure that I am not eating too much fat or my kids aren't eating too many eggs." (Latina)

"Maybe like keeping fresh foods. I mean, we try not to eat frozen foods, like microwave them all the time. Americans do that a lot and we realize that something from your garden or fresh like fish [is better]. You know, go back to the basics instead of buying those easy to prepare foods." (Asian American)

"I think it's really important that we eat the proper food and stay away from the salt and the fat." (Older)

"I play sports with my boys, just trying to keep up with them because they're 9 and 11, so I'm constantly chasing them." (American Indian)

"I try to do things like swimming because when you stimulate the mind and the body, you heal better." (African American)

Participants in all groups reported a high degree of compliance with the behavior encouraged by the basic informational message on mammography. Nearly every participant had had a mammogram, and many said that they did so on a regular basis. This probably can be attributed to their habit of having regular checkups, another nearly universal behavior among participants. As with their attitudes toward breast cancer and mammography, participants did not make sharp distinctions between the specifics of breast cancer screening or prevention and more general efforts to safeguard their personal health.

".but if you're always so busy and not in tune with your body and don't get regular checkups, not checkups when you feel bad, but checkups when you feel good. You have to know what's going on inside of you. And you can't be so busy and keep putting it off, putting it off, and end up sick and not even know you're sick." (African American)

"I go to the doctor once a year for a Pap smear and I go for a mammogram and I go to my doctors at least two or three times - about every three months, just to get a checkup." (Older)

"I think it's important to have a check-up at least once a year to find out what you have and don't have, especially cancer." (Asian American)

Also striking was the high proportion of women in each group indicating a knowledge and practice of breast self-examination (BSE). As might be expected, women who reported this behavior generally exhibited the proactive attitude mentioned above (see section 3.1.2). Women in all demographic categories discussed performing BSEs. As with diet, African American women mentioned BSEs least often while Asian American women did so most often. At least one participant concluded that BSEs were more effective than mammograms, revealing a potential for overconfidence in taking charge of one's own health.

Exchange between Asian American participants:

Moderator: Other than mammograms, is there anything else you do to check for breast cancer?

Response: Self-examination

Response: Self-examination

Moderator: You all do or..?

Response: Yes

Moderator: You do, you do, you do, you do.

Response: Oh, yeah.

Response: I don't do it often enough.

Response: You do it while you shower.

"And it is one of those diseases that if you're only using your hands to try to find a lump, that by the time you find it you're probably pretty close to not being able to survive it." (African American)

"I do my [breast self-exam] right after my menstrual period. That is when they taught us how to do it. That way, you can remember to do it." (American Indian)

"I do [the self-examination] in the shower. .I just see if any lumps or anything are in it." (Older)

"I believe more cancer is found by finding the lump yourself or your doctor finding it, rather than the machine." (American Indian)

In addition to mammography screening, regular checkups, a healthy diet, physical activity, and BSE, some participants mentioned health maintenance activities that fell into the category of "complementary and alternative medicine." These included:

- Faith practices, sun dances, sweats, and a general trust in the healing power of faith;
- Acupuncture, acupressure, chiropractic and shiatsu massage;
- Meditation, stress-reduction exercises, and positive thinking; and
- Crystal healings, use of magnets, and home remedies such as use of herbs.

Except in cases of financial distress, these practices did not seem to replace regular checkups or recommended mammography screening. However, discussion of "traditional medicine" revealed that some women feel something is lacking in modern medicine, despite their ultimate trust in their doctor.

".Like my Mom says, 'Look, your grandmother was 100 and something years old and she never went to any doctors. With little herbs and things at home, that's how she treated herself, you know, house remedies, and a lot of faith in God.'" (Latina)

"It's the Lord, you know. He's my lawyer; he's my doctor; he's my president; he's my mayor; he's my everything. And that's who I look toward, you know. I talk to Him every night, day, every time I get in that car of mine. He's right there with me." (African American)

"My medication was running outrageous prices and now I'm depending on the Lord to take care of me." (African American)

"There are a lot of herbs and things they pick on the mountain ...sage, where they burn the sage and a lot of ceremonial things. We make a sage tea when we're congested, or the elderberry for fever. This is what we learned from my stepfather." (American Indian)

3.1.4 Motivations

During the focus group discussions, participants revealed a wide range of motivations for getting regular mammograms and learning about breast cancer. These motivations were often tied to proactive attitudes and a general, if somewhat qualified, willingness to follow the instructions of a doctor. It appears that participants' high levels of reported knowledge and behavior with regard to mammography screening are also tied to an underlying motivation to stay healthy.

Participants most often stated that they got mammograms to ensure a high quality of life—to remain healthy and independent, to feel young and happy, to enjoy life, and to avoid pain. Because most women looked to their doctor to safeguard their health, this desire to have a high quality of life reinforced the motivation to follow their doctor's instructions.

"If you don't have health, you lose the desire to do anything, I think. You don't have any desire to clean, to work, to go out. So in actuality, you are not worth much, which is the main thing -- health is the main thing in a human being." (Latina)

"When you are healthy, you get up happily, you get up to do your daily chores, you take care of your children and go to work." (Latina)

"If you have your good health, you can go to work with pleasure, you take care of your children, you go out. With good health, everything is beautiful. When you hear music, you start to dance and sing, your stress goes away. When you see somebody who is ill, that person has stress and looks sad." (Latina)

"There's nothing like not having your health. I think if you've ever seen anyone go through being sick, you don't want to go there." (African American)

"For me it is important because my health is directly connected with my happiness. When I'm ill, because I'm ill so seldom, when I'm ill, there's a definite effect on my emotional stability." (African American)

"I just turned 40 and I see my grandma, how much she suffers, and I want to be healthy when I get to my grandma's age." (American Indian)

Closely related to quality of life was the motivation to stay healthy for one's family. With the notable exception of older and Caucasian women, women in all groups emphasized that they got mammograms or pursued other health-conscious behavior "for my family" or to enjoy their children. Nearly all women made at least some reference to their family when discussing the reasons why they placed a high priority on their health. This motivation was especially pronounced in the discussions with Latina women.

"Of course, I want to live to 100, I want to see my grandchildren." (Latina)

"If you don't take care of yourself, it's not only you that is suffering but your family as well." (Latina)

"It's very important that the mother is very healthy because [the children] depend on us more than their father." (Asian American)

"I have two children too and I'm a single mom. And so I have to be healthy because I'm the one driving them around and they depend on me, so I can't afford to be sick." (Asian American)

"I think if you have good health, your family is going to live better, because if you are healthy, it is the mom who runs the household, and she can take care of the household better. She can make sure that everyone else is healthy." (Latina)

"My daughter, she's 12 and I want to be there for her when she graduates from college and gets married and has children. Yes, for her sake." (American Indian)

"I want to see my granddaughter get married and have children too and she's only four." (African American)

"I used to pray when I was younger, when I first had children, that Lord please let me stay healthy long enough for my children to get grown. .and now I'm saying, Lord please let me stay healthy enough to see my grandchildren." (African American)

Nearly as compelling as the desire to maintain a high quality of life and to stay healthy for the family was the willingness to follow a doctor's instructions. Women often stated that they got mammograms because their doctor told them to.

"I don't think breast cancer when I'm having a mammogram. I'm going because my doctor said, 'Have a mammogram'." (African American)

"You don't go [get a mammogram] until your doctor tells you to go." (African American)

"No one ever told me to have a mammogram but the doctor." (African American)

"But the doctor told me, he said, 'You really need to have a mammogram every year', so I have been - it's part of my life." (Older)

".most doctors tell you, 'I'll see you next year.'" (Older)

"I think the bottom line is if you visit your doctor regularly, he's going to suggest that you go for a yearly mammogram." (Older)

"[The mammogram] was suggested by my doctor." (Asian American)

"When the doctor says, 'You need to go every six months'." (Asian American)

Despite the importance of the family, there was a tension between being healthy for one's family and looking out for oneself. Some women were able to resolve this tension by claiming that the two motives were one and the same, since their families were their greatest source of personal happiness. Others, far fewer in number, made a point of clarifying that any serious threat to their health made all other aspects of their lives secondary, including their families. Older women stressed the importance of maintaining good health in order to stay independent through the rest of their lives.

"I think we've got more women living by themselves now than ever before, for various reasons. Sometimes they have family in the area and sometimes they don't. Which puts even greater importance on maintaining your own health because if you don't, you may not have any help there to help you." (Caucasian)

"I think there's a sense of independence too when you're healthier and I think the modern woman wants that, that sense of independence, 'I can do it'. I'm not depending on my kids, I'm not depending

on my spouse, I'm not depending on whoever - the neighbors or the doctors or whatever to take me from here to there. ...I don't want to be a burden. I don't want to have my kids take me to the corner store. If I can do it now, just take some vitamins or don't eat salt, don't eat potato chips, then that might give me another five years. Even if it gives me another six months, it's worth it to me to be able to go to the store myself." (Caucasian)

"As much as you love your family and everything, you're not going to go [get a mammogram] for that. Alcoholics never quit drinking for their family. They only quit drinking for themselves. Gamblers don't quit gambling for their families. They can lose everything and they won't quit for their families or their loved ones. It's not a matter that they don't love them - they do. They do it for themselves. You quit smoking for yourself. Anything that you quit doing, you do for yourself." (Caucasian)

"If you don't love yourself, you can't love others. If you're sick, you can't take care of your family, because they are going to be sad and worried about you. They are saying you are going to be able to look after your family, because if you're healthy, you're going to be able to look after them better." (Latina)

"My kids are older, but I still don't want to die. ...it's not for your loved ones, it's for yourself. If you don't love yourself, forget it." (Latina)

"My health is first, because if I am not healthy, how am I going to work to support myself?" (Latina)

"For yourself, really. No one will do it for you. They say you are what you eat." (American Indian)

"If you can't take care of yourself, you can't take care of anybody else. You have to look out for #1." (American Indian)

"I like to be self-sufficient. I don't want to have to depend on somebody to do for me. I want to do for myself." (Older)

Fear of breast cancer was, understandably, quite high among most focus group participants.

This was most apparent in the strong negative reaction to the motivational message which specifically made mention of such fear – *If you're afraid of finding out you have breast cancer, getting a mammogram may give you peace of mind* (see section 3.3.4 below). However, women in most groups implicitly acknowledged that breast cancer was a source of considerable fear to them by their reactions to aspects of other messages. Explicit admissions of fear were much less common, perhaps reflecting the intensely personal/private quality of this emotion.

"Sometimes you are a little afraid because if you find a little ball there, a little lump there, it's like you feel 'oh my God, I'm going to die'. We get scared, that happened to me and I went to my friend [who] was operated on because she had cancer in both breasts and she didn't know it. We went five of us, one of us was afraid because she had a little lump, five of us went to do a mammogram, five friends. ...But you get scared, because they're glands, you get scared." (Latina, NY)

"So the word 'cancer' is .it scares you. There may be other things nowadays that are incurable as well but when you see the word 'cancer,' you see death. That's what you think of, that's what comes to your mind." (Latina)

Some minority participants -- Latinas, most vocally -- considered themselves to be at risk for breast cancer due to their ethnicity, which motivated them to get a mammogram.

"It is just like saying Blacks are at greater risk for high blood pressure. That doesn't mean you are going to have [cancer] or that somebody not Black is not going to have [cancer]. It just means that you are at a greater risk because of the studies that have been done." (African American)

"Hispanics ..have a higher risk ..because of our diet. ..We cook with a lot of fat. ..They say that Hispanics bring it from our ancestors, the indigenous people." (Responses from various participants, Latina)

3.1.5 Barriers

When asked about barriers that might prevent women from getting a mammogram, participants most frequently mentioned money as a factor. High fees and inadequate insurance coverage were considered to be the most likely obstacles to screening. This perception, however, was largely applied to other women; in nearly every group participants emphasized that they were able to get mammograms and knew of ways to obtain them without significant expense or trouble.

"A lot of women don't have the money to pay for [a mammogram]. They don't go because it's very expensive." (Latina)

Despite the perceived cost barrier, participants in all groups said they were able to get mammograms one way or another—if not through insurance or Medicare, then at clinics, hospitals, community centers, or through some other free avenue. Participants in every demographic category said they knew that either their own health insurance or Medicare provided free screening for its enrollees, and indicated that this knowledge motivated them to get a mammogram. Logistics, however, such as rearranging work schedules and inconvenient location of mammography facilities, often made the process of keeping a mammography appointment frustrating.

"When I happened to be 65, then you go on Medicare. .I know that they all send you a bill, and a statement comes [saying] 'This is not a bill'." (Older)

"It was really hard to go one place for the [doctor's] visit and another place for the mammogram." (Caucasian)

"It's easy to put things off like that and if it's going to hurt your pocket or your budget, it's even easier to put off." (Caucasian)

"I was always saying, 'I'm at work. I just can't leave. I can't go now and they're not open on Saturday'." (Older)

Some participants mentioned fear as a barrier, stressing that young women or women fearing a positive cancer test result might be too anxious or "stubborn" to practice recommended screening behavior.

"Other people don't go because they're afraid. They say, 'No, I don't want to find I have a disease, I don't want to know'." (American Indian)

"Because my neighbor just had both breasts removed. She had the test and in three months they told her there was a lump, but didn't do anything. Six months later, they removed the breast. In the

meantime, she had pains in her other breast. She asked the doctor to check that breast, and she had cancer in that one too. They took both of them. I am afraid of seeing it. It's frightening." (Older)

"I am afraid of someone saying to me, 'You've got cancer'. I think that is a reason why people don't go [get a mammogram]." (Latino)

"I have some small lumps, but I don't think there is anything. I touch those little lumps, but I haven't told the doctor, because I am afraid they are going to say it's cancer." (Latina)

Women, most frequently in the Latina, Caucasian, and Asian American groups, remarked that the physical experience of the mammogram procedure was unpleasant. The pain and discomfort caused by mammograms was mentioned often and insistently.

"If you have a lot up there and you get smashed, it makes you think of a boil or something, just popping." (Caucasian)

"I think because Asians have smaller breasts, that's what I heard, so it's like the machine is not made for Asians. It hurts." (Asian American)

"I had one that pressed so hard I could not stop crying because it hurt so bad. . .And I think that lady hurt us on purpose." (African American)

".I thought it was just traumatizing your tissue. Everybody would say, 'Ouch, I've just been for a mammogram.'" (Older)

"I just feel [the mammogram] is uncomfortable." (Latina)

"I have the mammogram every two years. . . . But other than that. I mean it is very painful." (Latina)

"Because a lot of women say it's so painful, I would say it's not as painful as they say. It's a bit uncomfortable, but it's not a pain you can't handle." (Latina)

Latina and American Indian women also mentioned embarrassment as an obstacle to getting a mammogram. Despite this modesty, however, they were not reluctant to discuss mammography with frank talk and gestures—a fact revealed by their body language during the groups. More than once, for example, participants in the Latina groups felt comfortable demonstrating how they performed their breast self-exams. In addition, a handful of participants across ethnic categories made comparisons between mammograms and Pap tests (and sometimes child birth), indicating that mammograms are much less embarrassing and painful than either Pap tests or child birth.

"I say I did, but I was embarrassed to tell him, no I don't touch myself, because we were brought up that we didn't touch ourselves." (American Indian)

"I am very shy and embarrassed to take these kinds of exams." (Latina)

"Even though it is a female doctor, I am embarrassed." (Latina)

"I know women who say they are not going to go. 'I am not going to show my body to a doctor'." (Latina)

"I don't think people are worrying about it hurting. It is people who are ashamed of being seen naked." (Latina)

3.2 RESPONSES TO THE BASIC INFORMATIONAL MESSAGE

The first message tested by moderators in all focus groups was a basic informational message:

Starting at age 40, all women should have a mammogram every one to two years.

Women in all focus groups responded favorably to this message, finding it clear and informative. This may have been due, at least in part, to the fact that some participants, most notably African American and American Indian women, had some previous knowledge of the screening guideline.

Beneath the surface of this approval, however, were some crosscurrents that could limit the effectiveness of this and the other tested messages. Many participants, for example, were confused about the significance of age as a risk factor. Partly because of this confusion they expressed a strong preference for language that did not specify a recommended age for regular screening, but was more inclusive. Group discussions were also influenced by anecdotal stories that led some participants to question the accuracy of mammograms, again casting doubt on the basic informational message.

3.2.1 Confusion about age as a risk factor.

Despite a widespread understanding that women should get mammograms, participants in all groups expressed confusion about the basic facts of breast cancer risk and mammography screening. The most common objection to the basic informational message, voiced most frequently in the Caucasian groups, was that women should get screening mammograms before age 40. Some participants, most notably in the older and Latina groups, emphasized that women should have mammograms more frequently than every one to two years. Others felt that everyone was at risk for breast cancer—including men—and that women ages 40 and older should therefore not be singled out. A few women were confused by mammography messages they had previously heard -- for example, those saying that women should start having mammograms at age 50, or that they should have a baseline mammogram at an age much younger than 40 years.

"[I disagree with the] 'at age 40' [portion of the statement]. I think it should be [based] on a person's health history and maybe, like she was saying, if she needs that at age 37 or 36 or 35 just to allay fears, then so be it. I don't think they ought to regulate it because a lot of people could have fibroids and it becomes something else, but they waited all those years when they could have found out earlier." (Caucasian)

"'Start at 40'. Don't need it. That's misleading. Because there's a lot of people, you know, young people prior to 40 who have breast cancer. So it's something that perhaps should not have an age there, you know. They should just check periodically. You shouldn't focus on age." (African American)

"That statement is misleading in another way also and none of us have thought about it - that men have to have them too." (African American)

"Why 40? You hear about people getting cancer, kids getting cancer, why does it have to be strictly for a woman at 40?" (American Indian)

"Why can't it be started when the girls get breasts?" (American Indian)

"It seems like younger and younger people are getting cancer." (American Indian)

"Even men, men are getting breast cancer a lot." (American Indian)

"The age 40, I don't like that statement. It's like an arbitrary number. Oh, I'm 39, I don't need to get a mammogram. Right." (Asian American)

"For me, the age 40 can flip flop so much. When I'm reading stuff, it was 45, and then it was 50. The age has changed a lot, and it was every two years, and then it was once every five years." (American Indian)

"I thought it was 50 now, next it will be 30." (American Indian)

"Okay, let's say I don't have breast cancer so what's the difference between me and a 15 year-old? And she's probably doing the same things I'm doing - eating the same things I'm eating. So is there a time limit that you have risk that they should be checked, or is it your overall body? You know, like an arm or leg. You don't get your leg x-rayed every year because they are legs. Why do you have to get your breasts examined, x-rayed? What's the difference between the breast and the ear?" (African American)

"I have a granddaughter who is seven and her little boobs are coming. In a young person like that, as she's growing up, I think she ought to have one." (Older)

"[The message] sort of implies that if you are under 40 you are okay. . .That's bad. It's very limited as to who the audience is. People who are below 40 are not even going to look at it." (Asian American)

3.2.2 Preference for inclusive language.

As discussed in sections 3.1.2 and 3.2.1, the widely expressed opinion that a person can get breast cancer at any age reflected a confusion about the cumulative effect of age as a risk factor. However, this same predisposition led participants to **respond positively to the inclusive part of the basic informational message: all women should have a mammogram.** Women in the older and Asian American groups were especially vocal in their approval of this specific part of the message. The prescriptive quality of this phrase also appealed to some women who placed a high value on personal health and prevention.

"I think every woman should have a mammogram." (African American)

"Cancer doesn't evade anybody..You know, wealthy people, poor people." (Older)

3.2.3 Anecdotal experience as a benchmark.

Participants were constantly testing messages against their own personal experience and the experiences of people they knew or had heard about. They considered this empirically-derived information more authoritative and compelling than nearly all sources of information other than a doctor's advice. Any perceived contradiction between their experience and a tested message—even if only partial—seemed to bias participants heavily toward disbelief or skepticism.

Group discussion was often influenced by personal testimonials in which women shared stories they perceived as contradictory to the basic informational message. These stories featured friends and family members who had cancer before age 40, leading to the conclusion that women should begin having mammograms at an earlier age, or have them more frequently than every one to two years.

"For me, I think it should be before age 40, because my in-law doesn't have any of her breasts. She's 47 years old. When she was very young, they were doing mammograms and they did a biopsy, looking at different parts of the breast. Time passed, and they took one breast, and time passed, and then she lost the other breast, and it was from the time that she was very young." (Latina)

"I know of two women who died, one was 23, of breast cancer. And one was 29. So, I started having them when I was about 33 or 34 at that time. One died within a year of each other. I started having [mammograms] at 34 and then having them every two years." (Caucasian)

"I have a niece that just passed away who had breast cancer. She was a nurse, and she went and got her mammogram, and they found a lump in her breast. They told her it was okay. Her breasts kept bothering her, and she went back and they found cancer. She lasted only six months. She was 42 and had two children." (Older)

"I have a friend who is very young and she has some lumps in her breasts and cysts.."

"My daughter has the same problem as your friend.."

"I have a girlfriend who has cysts.."

"I have a friend who was 32 years old when she had to have a mastectomy because she had cancer." (String of comments from various Latina participants in reaction to basic informational message)

"Because I've known people who had breast cancer at 20 and 30 and why are you going to wait until 40?" (African American)

3.2.4 Skepticism about the accuracy of mammograms.

The message implicit in many of participants' anecdotal stories was that mammograms might not be completely reliable. Many participants were also willing to state their skepticism explicitly: 12 of the 14 focus groups included discussion in which this sentiment was expressed. Participants in the Caucasian, African American, and American Indian groups expressed these doubts most frequently, but no ethnic group was immune. Such skepticism, on the other hand, needs to be considered against the nearly universal assertion among participants that they were having regular mammograms (see section 3.1.3). Apparently, doubts about the accuracy of mammography did not prevent women from getting a regular mammogram (or at least saying they did).

"I'm not sure the results of the mammogram are 100% sure." (Latina)

"I had a friend who had a problem, and they checked all the time. She went in December for the last check-up, and they noticed a lump. Within two months, she was gone. They just didn't see it." (Older)

"But the mammogram is not 100% anyway." (African American)

3.3 RESPONSES TO TEN MOTIVATIONAL MESSAGES

After participants responded to the basic informational message, the moderators presented them with 10 motivational messages, displaying them on boards around the room. (See section 2.2 for the text of these messages and a discussion of methodology.) Participants were asked to pick the two messages they considered most and least persuasive in terms of encouraging them to get a mammogram. Votes for most and least persuasive were then tallied by asking for a show of hands, and subsequent discussion focused on reasons why participants preferred some messages over others.⁵

Looking at the tallies across groups, it is clear that participants considered one message most persuasive and another least persuasive, while the remaining messages elicited more neutral responses. It is also worth mentioning that reactions to the least persuasive message were far more intense than were positive reactions to the most persuasive message. Despite these relatively clear aggregate trends, however, the variation among groups makes it difficult to generalize about the relative persuasiveness of any of the messages other than the least persuasive. The following sections are devoted to discussing the responses to each message separately.

3.3.1 Most persuasive message: "Mammograms detect breast cancer long before a lump can be felt. And finding it early can save your life."

This message appealed to participants in all groups, surpassing all other messages: 44 out of the 120 participants named it as their first choice. It was the only message for which at least one participant in all 14 focus groups voted it as most persuasive. **In addition, few participants considered this message the least persuasive:** it received the lowest number of "least persuasive" votes of all the messages tested in the 14 groups.⁶

The most commonly stated reason for choosing this as the most persuasive message was that it was positive and gave hope. The phrase "it can save your life" was singled out as particularly appealing because of its hopeful ring. This phrase was praised most frequently by the message's strongest supporters—Latina, African American, and American Indian

⁵ See Appendix D for the results of this vote ("Most and Least Persuasive Motivational Messages").

⁶ One other message had fewer votes for least persuasive, but it was tested in only two groups (older women).

participants—although at least one person in all but one of the groups specifically mentioned it as a compelling part of the message. Similarly, participants in most groups felt it was clearly stated and believable, and would persuade them to get a mammogram regularly.

"It has more of a positive spin on it, more preventative. 'Save your life' doesn't limit it as far as age groups are concerned. It's more futuristic and positive. Finding it early is positive." (Asian American)

"I do like that message because it doesn't promise anything. It's actually telling you something, but it's not beating you over the head with it. It's not saying you need to do it at age 40. It's very subtle. It instructs without promising and I do like that." (Asian American)

The overall popularity of this message, however, concealed some variation among supporters. While a majority of participants in five of the 14 focus groups chose it as most persuasive, in four other groups it tied with other messages as most persuasive.⁷ It received strong support in certain ethnic categories—in all Latina groups and, with more mixed support, in African American and American Indian groups. But this message did not stand out for older, Caucasian, and Asian American women: in none of the 6 focus groups in these categories did a majority identify this message as most persuasive, while a majority of one Caucasian group actually considered it least persuasive (the only group to do so). Older women did not find the message entirely believable because even if a mammogram were to discover breast cancer early, there is no guarantee that it would be early enough to save one's life. Older and Caucasian women again mentioned the fallibility of mammograms, indicating that they do not always detect a lump. Doubts about mammography's effectiveness were also demonstrated by comments in the Caucasian groups that the quality of a mammogram depends on additional factors such as breast size and breast density. Asian American women said they already knew the information in this message and reminded each other that mammograms do not always detect breast cancer, referring again to false negative results.

Although participants liked the fact that this message defined the purpose of a mammogram, some women revealed in discussion a fundamental confusion about how mammograms worked and what their purpose was.

"I question if that [statement] is true -- a mammogram detects it before you can feel a lump or if the lump can be felt sometimes right after a mammogram. I question the truth in that." (Caucasian)

"They all try to give so much credit to mammograms ..I mean, it gives you peace of mind, but it does not really, it's not a one hundred percent guarantee." (Asian American)

The response to the alternative version of this message—*Mammograms detect breast cancer long before a lump can be felt. And finding it early can save your life so you can be there for your loved ones*—was mixed. Although discussion in most groups indicated that women were motivated to safeguard their health for reasons relating to their family, this explicit rationale (“so you can be there for your loved ones”) was seen by some participants to be too obvious, inappropriately personal, or condescending (i.e., demeaning to a woman’s self-worth).

⁷ In one of these groups it received four out of eight votes for most persuasive, which for purposes of this analysis will be treated as a majority.

"For your loved ones and yourself." (Older)

"If I've got breast cancer, to hell with that. I'm serious. .If I have breast cancer, trust me, it is all about me now." (African American)

"It does not apply. I just cannot say I want to live so I can be there for you. I want to live period." (African American)

"I think this one is more geared toward mothers ..more toward family." (Asian American)

3.3.2 Second-most persuasive message: "Breast cancer can develop at any time."

The next most popular choice for most persuasive message—*Breast cancer can develop at any time*—was chosen by 31 participants. Like the most popular message (discussed above), this message also received few votes for least persuasive. Unlike the most popular message, however, the support for this message was scattered more diffusely across groups. A majority of only one focus group (American Indian) chose it as most persuasive, while it tied for most persuasive in three groups (both Asian American groups and one Caucasian group) and received a plurality of votes in two others (Caucasian and African American).⁸

Many participants liked this message because of its simplicity and directness, finding it both clear and credible. Because of the previously discussed lack of understanding among participants regarding age as a risk factor (see sections 3.1.2 and 3.2.1), this message appealed to those who held the widely expressed conviction that cancer can happen to anyone at any time in their lives.

"Even young people, even young males, can get breast cancer at an early age, so it can happen. Just because you don't get it, doesn't mean you can't. (Caucasian)

"I know a girl that died at 25 and she had breast cancer. That's why I said anytime. It doesn't have to wait until you're 40 and older." (African American)

"It could be men, women, or ..the 14 year-old girl. Doesn't have to be age specific so breast cancer can be developed at any time which is true. .So, it's an open statement that affects everybody." (American Indian)

"[It's my favorite message] because it's a very simple message. I can get it right away. Clear. I don't like to read. Every day so much things to read. Main message? Oh, you can have it any time so have it checked." (Asian American)

Those who disliked the message often gave the same reason for their response — namely, its simplicity—complaining that it had "no message" due to its shortness and vagueness. (Note: It is possible that this criticism might have disappeared if the message had been combined with the basic informational message stating that women should have mammograms every one to two years starting at age 40 (as in the composite PSA). On the other hand, some participants pointed out that this message was contradictory to the basic informational message, reasoning

⁸ A plurality represents the largest number of votes in a population that lacks a majority.

that if “breast cancer can develop at any time” then why should “women ages 40 and over...get a mammogram every one to two years?” This perceived contradiction may explain why the message was voted both most persuasive and least persuasive by a large number of participants.)

"It can happen anytime. What is 'any time'? At [age] 2, 6, 12, 40? That's the question I have. I mean, we're not telling 17 year olds or 20 year olds to go out and get a yearly mammogram, so that doesn't do anything." (African American)

"Right. So when I read this one, it's very powerful and simple, but, yet, it didn't give me enough information." (Asian American)

"To me, [the message] wasn't enough information." (American Indian)

Moderator: "Anything new in this message?" ...

Response: "Any kind of cancer can develop at any time."

Response: "Breast cancer can develop at any age."

Moderator: "Is that new?"

Response: "Yeah, because I never saw a woman under 40 with breast cancer."
(Asian American)

3.3.3 Message targeted to older women: "Just because a woman hasn't gotten breast cancer by age 65 doesn't mean she won't get it. In fact, her chance of getting breast cancer increases as she gets older."

This message was tested only in the two focus groups with older ethnically-mixed women, where it was chosen as most persuasive by the majority in one group and was one of two equally most persuasive messages in the other.

Most participants in the two groups of older women felt that this message was correct and important, even if some felt it was something they already knew. Both groups responded favorably to it, indicating that it was credible and clearly stated. A majority of one group found it to be the most persuasive motivational message. In the other group this message was considered equally persuasive as the most popular message discussed in section 3.3.1 above.

"I think you should have a mammogram whether you're 65 or 75. Lumps do come in your breast after a certain age, even if you get to 80. Because I had an aunt who had a lump in her breast at 90 years old, so I think you should have a mammogram every year." (Older)

"It lets us know not to get complacent because we've reached that age." (Older)

Because this message was deemed accurate and clear, modifying it did not seem to be a good idea. The alternative message—*Just because you haven't gotten breast cancer by age 65 doesn't mean you won't get it. In fact, your chance of getting breast cancer increases as you get older*—was less persuasive to the two older groups of women. The general sentiment expressed in the discussions was that the revised wording changed (and perhaps unduly personalized) an already effective message.

Moderator: "What can I say that makes this message better?"

Response: "I wouldn't change a thing. It's very clear."

Response: "I think so too. It just says the things in the order that it should be and it's very clear to me."

(Older)

"I don't like it because I'm 74 and I don't like that." (Older)

3.3.4 Least persuasive message: "If you're afraid of finding out you have breast cancer, getting a mammogram may give you peace of mind."

The negative response to this message was unmistakable, causing it to dramatically stand out from the others. Forty-one individuals registered their strongest dislike for it, with a majority of participants in four focus groups voting it least persuasive. Negative feelings about this message were not concentrated in specific ethnic categories: all groups had at least a few "least persuasive" votes for this message. Very few groups had participants who felt it was credible or persuasive.

More striking than the pattern of votes for this message was the intensity with which participants expressed their aversion to it. Most participants did not like its direct reference to the fear they felt about breast cancer. Focus groups in every ethnic category had discussions where participants indicated more than once that the word "afraid" should be removed from the message or replaced by the word "concerned."

"It's very negative. Afraid. Afraid of finding out. It's very negative. It's not scientific." (Asian American)

"Because if you're afraid of finding that you have breast cancer, you're not going to get a mammogram." (Caucasian)

"If I'm afraid of something, I will constantly put it off 'cause I don't want to know. It builds up more stress to me." (African American)

"But you'll be too afraid to go get the mammogram because you're thinking on the other side of the brain-- it might tell me I have it and I don't want to know about it." (Caucasian)

"...it doesn't mean that you're going to do anything about it. I might find out that I have a growth or something in my breast, but I'm afraid to do anything about it. I know it's there because the mammogram shows it, but that doesn't tell me to do anything with it." (Older)

Even more vexing to many participants was the suggestion that they might overcome being afraid of breast cancer by getting a mammogram. This idea was embodied in the second half of the message, "getting a mammogram may give you peace of mind." Critics reasoned that a positive test result would have the opposite effect, and that regular screening would raise the fear of a positive test result over and over again.

"I had a young lady who worked with me who another girl recommended she go have a mammogram. She went ahead. She had breast cancer. And it didn't give her peace of mind because she found she had cancer." (African American)

"I got confused. On one hand you are afraid, which means you are not going to go and find out. But when you go and get the check-up you are going to feel worried. So you are not going to have peace of mind." (Asian American)

"If someone really didn't know anything about [mammograms], [this message] might say to someone a mammogram will take your cancer away. What do they mean it gives you peace of mind? If you have cancer, peace of mind is not going to be there." (American Indian)

"Okay, if I'm afraid, okay, I get the mammogram. What if then something happens? What it does, it takes away the guess work - do I have it or don't I have it. But it is not going to do a thing for that fear." (African American)

"You're going to think the opposite side of the fence, that getting a mammogram is going to prove you were right." (Caucasian)

"To me, I thought it gave a false sense of security in that, okay, I had the mammogram done and if it comes up no, there's nothing wrong, then you may get relaxed and say, oh, I don't have it and may not think about it or do the things you need to do. ..It is kind of like you go to the doctor and they take your blood pressure and it is down and you say, okay, let's go get the ribs now." (African American)

"How about saying 'forget your fear'. To get peace of mind, do this [get a mammogram]." (Latina)

Although this message elicited strong negative reactions, it also drew some favorable comments, especially from older and Latina women. These participants liked the encouragement the message seemed to offer as an antidote to fear and paralysis. Interestingly, enough women voted this as their most persuasive message that it came in third after the two most popular messages discussed above.

"It's a loaded one. If you have cancer, you're not going to have peace of mind. But, if you don't have cancer, you will get peace of mind." (American Indian)

"It can very easily be benign." (Older)

"I am not afraid of finding out what I might have." (Latina)

Moderator: *"What did you like about this?"*

Response: *"That it's as if a doctor was telling us this. As if a doctor were to talk to you, because after you get a mammogram, they send you a note and you will be left with peace of mind, but if they say ma'am, please come in, because we saw something that is not normal, some kind of lump, that is when you might start." (Latina)*

"We can be there for our family...You're the mother. You have to comfort your child. A child tells you 'I have cancer, Mom,' and she is only 32 years old, what are you going to do? You have to be the strong one. She has to face that doctor. You do what you can. Go and get this done. Find out for sure. Why sit around and wonder about it. It won't go away by itself." (Older)

The alternative message—If you're concerned about getting breast cancer, getting a mammogram may give you peace of mind—was clearly considered more persuasive by women in every ethnic group but Latina. This reflects the strong aversion most women had to the use of the word "afraid" in the original message.

"The first [message] would scare you half to death, because of the fact you are going to find out what you don't want to hear. This one here, a little concern can save you." (Older)

"Concern, you know, to me is like thought-provoking. It's not something for me to dwell on. . .But afraid, . . .is like wait a minute, I'm out of here." (African American)

"It softens it. . . .It's not promising you nothing." (American Indian)

3.3.5 Less persuasive message: "Each and every woman age 40 or older is at risk for breast cancer, even if no one in her family has ever had it."

This message received mixed and mildly negative reactions. It was chosen as least persuasive by a majority of women in one of the older focus groups, and tied for least persuasive in one of the Latina groups, but was also tied for most persuasive in two Asian American and one Latina group.

The strongest (but not widely shared) objection was to the specification of age 40 as a point of demarcation, which some considered arbitrary due to their confusion about age as a risk factor. A few expressed surprise that age 40 had any special significance for risk of breast cancer, while others simply did not know that getting older increased one's risk. The phrase "each and every woman," on the other hand, elicited some support due to a belief in the randomness of who gets cancer.

"I repeat again, cancer has no age. Cancer has no age. They should take the 40 out. They should say 'all women run the risk'. All women run the risk, that's what they should put." (Latina)

"At 40 you could be as healthy at 40 as you are at 18. And . . .a three month-old baby in our family almost died from whatever. Exposed to the world. So he didn't have no more chance than I did at 50 than he did at three months." (African American)

"[It's not positive] that it's just targeting women who are older . . .because young people get it too." (American Indian)

"And you don't have to be 40 years old to have it." (Older)

Participants in all groups except older women tended to like the "despite family history" qualifier. A number of participants expressed support for this last portion of the message, partly because of the widely held assumption of universal risk for breast cancer discussed above (see sections 3.1.2 and 3.2.1). It also appealed to participants whose proactive stance toward personal health predisposed them to accept warnings against being complacent.

"I like the fact that you say even if no one in your family has ever had it. That's to let anyone [know] you can get it. But you need something that's gonna bring it out to them to the point where they're gonna be concerned enough to have a mammogram." (African American)

"It caught my attention because no one in my family has had breast cancer. It is important for me to have regular checkups and do regular breast exams. It's sort of frightening to think you could still get it." (Asian American)

3.3.6 Less persuasive message: "As a woman grows older, her chance of getting breast cancer increases."

As with the previously discussed message (see section 3.3.5), most groups viewed this in mildly negative terms; the main reason for disliking it was the explicit reference to women aging. Clearly, for many middle-aged women, just the mention of the word "older" was a turnoff. Participants in all groups, except older women, were uncomfortable with the use of this word. Some felt insulted by it.

Participants' lack of awareness about age as a breast cancer risk factor explained why they frequently stated that older women should not be singled out in this message. Basically, two types of confusion seemed to drive perceptions that this was not a persuasive message. The most important was a failure to understand the basic notion of what a risk factor is. But accompanying this misperception was a failure to recognize the difference between growing older and being old. Dislike of any reference to old age was so strong that it erased the distinction, causing many participants (with the exception of older women) to summarily dismiss the message or view it negatively.

"Since I'm not old, I'm not going to get the exam. So that's the idea, it's not only the word 'ages,' but also the word 'chances'. You know, it's like, well it's a chance that I might, it's a chance I might not, so why am I going to bother? I'm not going to fall in that group, I'm not falling within that group of aging." (Latina)

"A woman gets this picture mentally from 'as I get older': a wrinkled old woman that's half dead." (Latina)

"Older women, to me, are totally different than we are now. When my grandmother was 58, she was old. I think some women that still have that concept of being old at a certain age are reluctant to do things like have a mammogram." (Caucasian)

"This statement..hits you in the face. We know it. It just really bothered me. All this stuff when you get older. Hysterectomy, menopause, sweat, hot flashes." (Caucasian)

"You know once you turn what 30-35-40, and it's like you're older, it's like everything goes down hill." (American Indian)

"Your chance of getting breast cancer increases at any age because of the environment and everything else. Just the part of segregating because you are older [made it not believable for me]." (American Indian)

"They are taking away our years, years of life." (Latina)

"They are talking about us getting old." (Latina)

"Just that word, getting 'old', is an ugly word because we don't want to be told that." (Latina)

"[When we hear the word 'older', we think] that there is nothing we can do about it, that our food is going to hurt us, we can't do the things we used to do, that we are finished." (Latina)

"It makes me feel older." (Asian American)

Reactions to the alternative message—“As you grow older, your chance of getting breast cancer increases”—were mixed. **Most group discussions indicated that it was a bad idea to personalize a message that was already seen as unappealing.** The African American groups were in some disagreement on this point, however, with several participants indicating that a more personalized approach made the message more positive.

"It's negative, talking about age and growing older, it's negative. Even if they put it personally, using 'you.' The message is completely negative. Because there are people who are 100 years old, 80 years old, and they don't feel old, so that message is not going to say anything to them, and they don't have cancer." (Latina)

"I don't like anybody sticking their finger in my face." (Caucasian)

"When a person sees you as you, you're talking directly to me now. A woman, that's everybody else. When you see it says you, your chances, you read it and subconsciously it becomes personal." (African American)

"It just seems intimidating. As I grow older, my chance of breast cancer... I don't want it to be all about me." (African American)

"It's directed at me and I don't want it at me. I want it at every woman in this case." (African American)

3.4 RESPONSES TO 1-800-4-CANCER AND BROCHURE

In addition to the basic informational message and 10 motivational messages, moderators constructed and tested a makeshift, composite PSA in each group by combining the basic informational message, the most popular motivational message selected by that group, and a call to action featuring NCI's toll-free information line: "Call 1-800-4-CANCER. Cancer information from people who care." The three elements of the PSA were presented together on an easel. Moderators also showed participants a brochure on mammograms to see if the visual image portrayed on the cover was appealing. Participants were asked to comment on the brochure's general "look."

3.4.1 Public Service Announcement (PSA)

The consensus in most groups was that the PSA would motivate them to call 1-800-4-CANCER to learn more about breast cancer and mammography. However, a vocal minority in at least one focus group from every category except Latina emphasized their dislike of impersonal automated voice systems frequently used by 800 services. These women indicated that they would only use the 800 number if it connected them to a "live person" who could respond to their personal concerns. Some participants said they would turn to their doctor with their questions before calling the 800 number.

"These days, you call these 800 numbers and get a recording. You never talk to anybody." (American Indian)

"They'll tell you to punch a number button. You punch that button, you punch another button. .I'd rather talk to a real live person, an individual." (Older)

"I have my own doctor to go to, but for people who have no insurance and no income and don't speak English, that would be the number to call." (Asian American, assuming the person answering the phone would be able to answer questions in languages besides English)

A handful of participants expressed their dislike of "4-CANCER" because it sounded like "for [in favor of] cancer," and cancer is not a word they want to see used explicitly (i.e., advertising the information service with only the numbers of the telephone line would suffice).

After hearing initial reactions to the call to action ("Call 1-800-4-CANCER. Cancer information from people who care"), moderators asked participants if changing the word "care" to "know" would make the PSA more effective. Participants tended to vacillate over which of these terms they preferred, but concluded that a PSA encompassing both concepts -- caring and knowledge -- would be most effective. They were also very much in agreement that a successful PSA should include credentials identifying an authoritative source of information.

"Caring is softer, but the word 'know' would make you feel like they probably have had the experience and you might feel better talking to them." (Caucasian)

"Maybe if they added both ['care' and 'know'], they wouldn't have a problem." (Latina)

"[The National Cancer Institute is] a little more knowledgeable than ..whatever answer that person who cared gave me. .I mean, my pastor would care, but he wouldn't know about breast cancer. .If the National Cancer Institute wasn't there, it wouldn't mean a thing to me." (African American)

"I think 'people who know' is better because you feel even more sure that they are going to answer your questions properly ..these are people who are going to give us more complete and reliable information, because they know, more than simply just wanting to help." (Latina)

"From all the discussion we had around here, it seems like we would really like cancer information from people who know about it because the whole time we've been saying, 'Is this really true or is this so and so?'" (African American)

3.4.2 Brochure

After discussing the PSA, participants evaluated the "look" of a brochure on mammography (see Appendix E for a copy of NIH Publication No. 97-3418 -- "Mammograms: Not just once, but for a lifetime. "). The overall response to the "look" was positive in all but one African American focus group, which found it sad and a little confusing. Because of the highly proactive stance that many participants took toward their health, most indicated they would pick up and read the brochure. The visual quality and the relatively large print of the brochure was an important facet of its appeal. Opinions were divided on whether photographs or artwork were preferable, but one thing seemed to be clear in all groups: images featuring ethnic diversity and/or multiple generations of women belonging to the same family would make a brochure on mammography most relevant and appealing.

"I like the Black woman as the nurse. the technician. And that they have different races..." (African American)

"[I would put] Native people on the cover. . .Native dress, maybe the jewelry." (American Indian)

"I like the grandmother/mother/daughter thing..." (Older)

When asked about the use of spokespeople to promote mammography, participants in most groups indicated that they would prefer testimonials from ordinary people over the use of celebrities as spokespeople. Participants seemed to be affected most during the groups by the personal stories of breast cancer survivors. As one Latina woman suggested, a celebrity would have more credibility in the role of spokesperson if she were also a breast cancer survivor. Such a celebrity could then appear in public events and PSAs alongside everyday people who also survived breast cancer.

"If you want to target say Black women, you could have Black women spokespersons who are not necessarily celebrities, but that look like you and me and sound believable." (African American)

"I think it would be great to see someone who has had cancer." (Latina)

"If this famous person has suffered cancer, it would influence us more." (Latina)

"Testimonials of people that didn't take care of themselves on time and had their breasts removed or even lost their lives ..often with testimonials, that is when you can inspire people to get a mammogram." (Latina)

"We had a health fair in June. We had a young man that is in the movies. But they get only a certain group. They don't understand, or maybe they do, but it doesn't come across that way. We tried to bring one celebrity in. It doesn't capture everyone's attention. It is different in our community. We [live] up in the mountains." (American Indian)

"I think it should be everyday people. . .With a celebrity you might look up to them but you don't always identify with them." (Asian American)

"Sometimes that's nice, someone who is concerned about their results, they could talk to another survivor, someone who has been through it. That would be a reason to call. To talk to someone more personally involved." (Asian American)

4. CONCLUSIONS AND RECOMMENDATIONS

4.1 CONCLUSIONS

The following conclusions and themes, applicable across ethnic groups, can be drawn from this focus group study:

4.1.1 Women have a proactive stance toward health in general, but only a basic level of knowledge about mammography and breast cancer

Women actively embrace information pertaining to their health. However, while the vast majority understand that they should get regular mammograms and that doing so checks for early signs of breast cancer, many are confused or skeptical about inconsistent breast cancer and mammography messages (e.g., when to start mammography and recommended screening intervals), the effectiveness of mammography, and the competence of mammography technicians.

4.1.2 Messages about mammography and breast cancer should tell women why they should get regular mammograms and not explicitly focus on fear or age

Deeply ingrained perspectives on health played a part in women's responses to the tested messages. Some of these, such as a positive attitude to learning about and maintaining personal health, encouraged receptiveness to the messages. Other perspectives, such as a general skepticism about health information, dampened receptiveness or interfered with the communication of certain concepts (e.g., that aging contributes to breast cancer risk in a cumulative way).

The most successful motivational messages tested in the focus groups had a tone that was both informative and hopeful. Across focus groups, the following message elements were viewed most positively: breast cancer can develop at any time; all women are at risk – even those age 65 and older, or those without a family history; mammograms can detect breast cancer early; and early detection can save lives. In general, the composite PSA message was perceived as most effective because it not only encouraged women to get a mammogram but also included the additional element of a call to action (calling a toll-free number for more information).

On the negative side, the least persuasive messages made explicit references to issues that were considered turnoffs – namely, fear and age. Participants, except for those age 65 and older, were uncomfortable with messages targeted by age and, in some cases, by gender. Many felt that cancer was a risk for all people (some going so far as to point out that men can get breast cancer), stating that older women (i.e., over 40) should not be singled out. The notion of a mammogram being able to “save your life” was persuasive not only because it was positive but because it did not distinguish between age groups. In general, messages that seemed to tell

women what to think were deemed offensive, while messages that were phrased as explanation or encouragement were more effective.

4.1.3 A doctor's authority and personal experience, including knowledge of other women's experiences, are the most trusted sources of health information, despite some uncertainty and questioning

The two perspectives most commonly adopted by participants—trust in a doctor's authority and reliance on experience, one's own and others'—could both impede and facilitate the communication of message concepts, depending on the message and the personal history of each woman in the group. For example, if a participant knew someone who waited till she was 40 years old to get a mammogram and "it was too late," then this woman may not trust a message that included age 40 as a point of demarcation (e.g., "Starting at age 40, all women should have a mammogram every one to two years").

Nearly all women in the groups had personal experience with mammography and recognized the importance of following the basic informational message even if some questioned it. Interestingly, this was true despite the almost universal view that mammograms are painful or uncomfortable. This seems to have been largely the by-product of trusting the judgment and recommendations of doctors.

Women turn to many sources of knowledge (e.g., personal, friends', and family experiences; hearsay; folk wisdom; "alternative" medicines) to supplement what they learn at the doctor's office. In the end, however, doctors constitute "the final word" on health advice.

4.1.4 Women are not lacking in exposure to communication channels

A broad range of communication channels were mentioned by participants as sources of information on breast cancer and mammography: print and broadcast media, the Internet, social services, clinics and hospitals, and other public or official places. While all of these channels were considered less authoritative than the advice of a doctor, it is clear that many women utilize these sources as part of their generally proactive orientation toward personal health.

4.2 RECOMMENDATIONS

The results of this study indicate that none of the 10 motivational messages tested would be effective, in its current form, in appealing to all of the ethnic groups included in the research. A new, unique message should be created, integrating elements of the most successful messages tested and striking a tone that is both informational and hopeful. Elements of the two most successful messages were as follows:

- Breast cancer can develop at any time

- All women are at risk – even those age 65 and older, or those without a family history
- Mammograms can detect breast cancer early
- Early detection can save lives

Interestingly, the first two of these elements deal with the reality and underlying fear of breast cancer, while the latter two represent more of a solution or a sense of hopefulness.

In creating a new message (e.g., PSA), it will be important to make sure that the elements that are combined are not in conflict with each other or with the mammography screening guideline. Some participants, for example, noted that the messages *Breast cancer can develop at any time* and *Early detection can save lives* are in conflict with the basic informational message, *Starting at age 40 all women should have a mammogram every one to two years*. Why, they questioned, should a woman wait until age 40 to begin having mammograms if breast cancer can develop at any time and early detection saves lives?

Based on this study, the following recommendations related to message and PSA design should also be considered:

4.2.1 Personalize messages

Consider framing a message in the form of an intimate personal story, such as a woman relating a story told by a friend or a sister. Keep in mind, however, that messages which get “too personal,” especially when touching on deep fears about cancer, may backfire, especially if they include directive words such as “you” or “your.” Given that women seem to obtain information on mammograms from their family and friends, an intervention that taps into women’s social networks would likely have an impact. Men could also be the primary target of messages to motivate the women in their lives to get a mammogram. Personalized reminder messages sent to women’s homes, similar to the way dentists send reminders for regular checkups, would be another effective motivator. Furthermore, because of the attractiveness of personalized attention when calling a 1-800 number, the PSA could include a statement informing the reader that she will be connected with a live person to answer her individualized questions.

4.2.2 Use testimonials from "ordinary" people who are cancer survivors

Participants were very affected by their family and friends' stories of breast cancer survivors. A celebrity would have credibility in the role of spokesperson only if she were a breast cancer survivor herself. Such a celebrity could appear in public events and present PSAs alongside "everyday" women who also survived breast cancer. Testimonials from "ordinary" people providing facts and statistics would be both persuasive and educational.

4.2.3 Call upon the authority of a doctor

Try to include the figure of a doctor in the message. Most women wanted expert knowledge, although a caring expert was most appealing. The gender of the doctor was a topic that surfaced in all groups; women appeared to prefer visiting a female doctor, if available, to reduce the anxiety of getting undressed (a barrier to seeking mammograms for many women of Latina and American Indian background).

4.2.4 Evoke fear but do not name it

Use fear of cancer positively; do not mention fear, per se, or use “scare tactics.” This can be done gently by acknowledging cancer's fatal potential within the context of a more prominent reassurance that leads the reader to recognize the value of regular mammograms. For example, have a woman tell a story about her sister who got breast cancer, struggled with the treatment she received, but survived it. (The story has a positive resolution so the reader sees breast cancer as a threat but does not get fatalistic.)

4.2.5 Involve family but do not preach

Use the image of a happy and healthy family as a motivator for health-seeking behavior, since women in all groups mentioned their family as a major reason for staying healthy. However, some women resented being told explicitly that they ought to have a mammogram in order to “be there for their family.” One Caucasian woman visualized “a commercial..where you would have children and families at a picnic or something like that”; she astutely realized “you could get a message across subliminally without stating it or speaking it.” Messages that combine family and self-concern as reasons for healthy behavior would hold the greatest appeal.

4.2.6 Explain the significance of age 40

Messages targeting women 40 and older should give an explanation for choosing this age demarcation. Many women in the focus groups challenged what they perceived as the arbitrariness of age 40 in the basic informational message. At least one participant also wondered whether there was an upper age cutoff (e.g., “70 years of age”) for obtaining mammograms.

4.2.7 Clarify the risk factor of aging

The cumulative effect of aging as a risk factor was lost on many women, regardless of how old they were. Participants, especially those in the 40 to 60 age bracket, tended to ascribe negative connotations to the notion of age, or the word “older,” viewing it as inconsistent with their self-image. Messages need to convey clearly what it means to be at higher risk as you age.

4.2.8 Pay close attention to language

Each word in a message should be chosen carefully. Replacing just one word in a message with another was often enough to change participants' reaction to the message entirely. The most common example of this was the positive reaction that occurred when the term "concerned" was substituted for the term "afraid." Women also thought words such as "interested" or "doubts" could express the same idea without a specific reference to fear (e.g., "If you are *interested* in learning more about breast cancer, [call to action]," "If you have *doubts* about whether you should get a mammogram, [call to action] ").

A similar observation was made for the concept of "growing older": women tended to prefer terms like "matures" or "develops." There was even some discussion about the use of the word "women." One participant suggested using the term "females" instead of "women," because the latter had the connotation of "older" women, implying younger women would be excluded. While using the word "you" (instead of "woman") would extend the message to men as well as women, it would also run the risk of being too personal for many women. For some participants, just seeing the word "cancer" (e.g., "1-800-4-CANCER") or "breast" in "breast cancer" was enough to induce anxiety.

Another example of the importance of language came from participants' debate over whether to use "Cancer information from people who care" versus "Cancer information from people who know." Overall, participants seemed divided about which term to use ("care" or "know"), and concluded that a PSA encompassing both concepts -- caring and knowledge -- would be most effective. The combination of ".people who care" with a reference to NCI might be best because it appeals both to participants' overall preference for a personalized approach and to their trust in the established expertise of a national authority on cancer.

Care should also be taken in the choice of helping verbs and qualifying phrases. The verb "can" in a message about mammography was too definitive for some women while "help," "may," or "could" seemed to allow for the perceived fallibility of a mammogram. Preference for the phrase "is at a greater risk" rather than "is at risk" was mentioned as an option that could reduce confusion over the concept of risk.

In some cases, adding a qualifying phrase to a message may help women better understand the complexities of breast cancer. For example, most participants assumed that family history has a strong relationship to one's chance of getting breast cancer. Upon seeing the message, "Each and every woman age 40 or older is at risk for breast cancer, *even if no one in her family has ever had it,*" many women were surprised to learn that the absence of family history did not necessarily translate into not being at risk for breast cancer. Visuals and graphics, such as bar charts, could also be very useful in helping women learn the facts about mammography and breast cancer.

Language choice is also important for Spanish speakers. In this study, symptom ("síntoma") was preferred over protuberance or lump ("protuberancia"), as were breast ("seno") over chest ("pecho") and mammography ("mamografía") over mammogram ("mamograma"). Instead of using the word "protuberancia" for lump, "nódulo" (nodule) may be clearer to Spanish speakers.

A P P E N D I C E S

Appendix A: Participant Recruitment Screeners

Appendix B: Moderators' Discussion Guides

Appendix C: Note on Method of Analysis

Appendix D: Most and Least Persuasive Messages

Appendix E: Brochure – Mammograms: Not Just Once, But for a Lifetime