Modifying a Breast Cancer Risk Factor Survey for African American Women

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Purpose/Objectives: To evaluate a breast cancer risk factor survey for use with African American women.

Design: Two focus groups consisting of women randomly selected from the patient population of Henry Ford Health System in Detroit, MI.

Setting: A large, vertically integrated, private, nonprofit health system.

Sample: Focus Group I consisted of 11 African American women aged 18–50, with a mean age of 41 years. Focus Group II consisted of nine African American women aged 51 and older, with a mean age of 60.9 years.

Methods: A qualitative approach was used to gather and interpret the focus group data.

Main Research Variables: Perceptions of a breast cancer risk factor survey and perceptions of breast cancer risk factors.

Findings: The focus group participants suggested ways to improve the survey. Women in the younger age group appeared to lack awareness regarding breast cancer risk factors. Women in the older age group reported not knowing their family health histories.

Conclusions: Based on comments made by the focus group participants, the survey was modified substantially. Breast cancer risk factors were perceived differently by women in the two age groups.

Implications for Nursing: Results of a survey of a large, ethnically diverse sample of women could inform the development of culturally and age-appropriate nursing interventions designed to address breast cancer risk perceptions and enhance the likelihood of adherence to recommended mammography screening guidelines.

American women have not benefited as much from advances in breast cancer early detection as Caucasian women. This finding is corroborated by other researchers as well (McCarthy, Yood, et al., 1996; Yancey, Tanjasiri, Klein, & Tunder, 1995). Differential breast cancer screening practices may contribute to disparities in breast cancer diagnoses and treatment outcomes by racial group (Howard et al.; McCarthy, Ulcickas, et al., 1996; McCarthy, Yood, et al.; Philips, Cohen, __________)
As postulated in the benefits of medical care component of the Health Belief Model (Becker, 1976; Jones, Jones, & Katz, 1991), a woman’s adherence to professional advice regarding breast cancer screening is based on her perception of susceptibility to breast cancer weighed against an estimate of barriers that might be involved in undertaking breast cancer screening (Barroso et al., 2000; Becker; Bosompra et al., 2000; Crump, Mayberry, Taylor, Barefield, & Thomas, 2000; Jones et al.). Perceptions of breast cancer risk appear to affect breast cancer screening behavior (Bailey et al., 2000; Pearlman, Rakowski, Ehrich, & Clark, 1996; Roberson, 1994; Stein, Fox, Murata, & Morisky, 1992; Womeodu & Bailey, 1996; Yancey et al., 1995). Previous research suggests that African American women express more doubts about the efficacy of medical care and feel less at risk for breast cancer than Caucasian women (McCarthy, Yood, et al., 1996; Pearlman et al.; Yancey et al.).

Culturally appropriate breast cancer risk factor surveys can be used to identify women who might need more intensive breast cancer screening promotion and surveillance following abnormal screening results. Clinical decision-making algorithms and public policies typically are based on the results of research using measurement instruments. These algorithms and policies affect the manner in which health care is provided. Therefore, assessing the appropriateness of measurement instruments for use with specific population groups is important.

Understanding how African American women perceive survey questions designed to elicit information about breast cancer risk can be useful, leading to modifications of these questions to make them more culturally appropriate and resulting in higher data quality. In addition, understanding perceptions of breast cancer risk, which may be based at least partially on knowledge of breast cancer risks, can enhance the development of breast cancer screening interventions to maximally reach African American women by addressing culturally based perceptions (Chu, Baker, et al., 1999; Chu, Tarone, et al., 1999).

The purpose of this study was twofold. The first goal was to use data from two focus groups held with African American women to modify a breast cancer risk factor survey. The second study goal was to assess the perceptions of breast cancer risk factors held by the focus group participants. The present study is part of a larger study funded by the U.S. Department of Defense. The aim of the larger study is to define molecular markers and their interaction with other epidemiologic risk factors, particularly exposure to estrogen, that can serve as risk indicators for subsequent development of breast cancer among African American and Caucasian women. The epidemiologic risk factors will be identified through the use of the survey evaluated in the present study.

Methods

To accomplish the study goals, two focus groups were held with African American women. Focus groups were chosen as a mode of data collection because they can be a rich source of information. In a focus group, data are collected from a homogeneous group of individuals using a predetermined, structured sequence of questions in a focused discussion (Kohler et al., 1993). In general, focus groups are conducted with individuals representative of the population(s) that will complete the survey. Focus groups can help to develop or modify questions that have meaning for particular populations and allow for an in-depth exploration of the knowledge, attitudes, and beliefs of specific cultural groups (Bailey et al., 2000; Beaudin & Pelletier, 1996; Bulmer, 1998; Nymantti & Shuler, 1990; Vuckovic, Ritenbaugh, Taren, & Tober, 2000).

Survey Instrument Evaluated During the Focus Groups

Topics covered in the breast cancer risk factor survey included contraceptive history, hormone medication history, menstrual and menopausal history, general medical history, alcohol and tobacco use history, physical activity, home ownership, and contact information. In addition, general background information was solicited, such as location of birth, religious affiliation, marital status, paternal and maternal ancestry, and educational level. The original survey was a compilation of items from a number of commonly used epidemiologic cancer risk factor surveys. The focus group participants were asked to provide their opinions regarding the survey.

Sample Selection

The methods used in obtaining the study sample are shown in Figure 1. The Henry Ford Health System (HFHS) Corporate Data Store, an administrative database, was used to randomly select potential participants who were African American women aged 18–50 years (Focus Group I) and aged 51 and older (Focus Group II) who made at least one visit to HFHS in the first six months of 1998. Two age groups were included in the study to determine whether perceptions of breast cancer risk differed by age group. Random sample selection was deemed appropriate to represent the population of African American women in the included age groups. Kohler et al. (1993) suggested including 8–10 participants in focus groups.

From the list of potential participants, researchers randomly selected women to be called by telephone and invited to participate in a focus group. Researchers conducted a short eligibility screening during the invitation call, where they also offered the women a $40 honorarium. Eligible and interested women were sent a written confirmation of their focus group date, time, and location. Transportation to the focus groups was not provided. The women received a reminder call the night before their scheduled focus group session.

Researchers developed a 20-page, moderator’s structured interview guide based on the breast cancer risk factor survey. A sample set of questions from the moderator’s guide referring to a specific table in the breast cancer risk factor survey included “Are the instructions on how to fill out the table clear to you? If not, how could they be made clearer? How would you feel if you were asked to complete this table? Are the words in the table clear to you? If not, which words would you use to describe these things? How does the layout of the table look to you?” Women in both age groups were asked exactly the same questions regarding the survey.

The focus groups took place at a HFHS research office located in Detroit, MI. The moderator, assistant, and recorder at each focus group were African American women under age 40. The two-hour focus groups were videotaped and audiotaped. In addition, written notes were taken during each focus group as a supplement to the mechanical recording devices (Sim, 1998).
Prior to each focus group, participants signed a consent form and received a packet containing a nameplate for identification, a copy of the survey to be evaluated, and a body image pictograph. The pictograph was used in conjunction with the survey so the survey respondents could identify their body size at different ages. The purpose of the focus group was explained, and participants were encouraged to speak freely. Confidentiality ground rules were laid. The focus groups began with an icebreaker. Following the completion of the focus groups, participants signed a receipt and were given a $40 honorarium.

Analysis

Content analysis of the focus group transcripts was conducted following the approach used by Vuckovic et al. (2000). Investigators independently coded the transcripts to index categories of responses and checked them for accuracy against notes taken during the focus groups (Beaudin & Pelletier, 1996). The coding process provided a systematic approach to identifying themes in the data (Thom & Campbell, 1997). Statements identified from the data were open-coded and grouped into conceptual categories, themes, or axial codes by consensus among the investigators (Bulmer, 1998; Nymanthi & Shuler, 1990; Thom & Campbell). Themes related to survey questions that were common across both age groups were identified, as well as themes unique to a particular age group. These themes are identified in Figures 2–6.

Results

Focus Group I consisted of 11 African American women. The mean age of the women in this group was 41 years, with a range of 29–48 years (SD = 6.3 years). Focus Group II was composed of nine African American women. This group had a mean age of 60.9 years, with a range of 51–77 years (SD = 8.2 years).

The study results are organized around the two study purposes. The first goal was to describe suggestions made by the focus group participants to improve the survey; the second
was to describe perceptions of breast cancer risk expressed by the focus group participants.

**Suggestions to Improve the Survey**

Participants raised concerns about the confidentiality of the information provided in the survey. Although the women in both age groups appeared to be concerned about what would be done with the information provided, one woman in the younger age group appeared to confuse the meaning of the terms “confidential” and “anonymous” (see Figure 2). The original survey stated “All information you provide will be kept confidential.” In the final survey, the term “confidential” was explained in the following manner: “All information you provide will be kept confidential and will not affect your medical care. Only the researchers involved in this project will see your answers.”

Women in both focus groups reported having difficulty answering survey questions because they could not remember their menstruation history, contraceptive history, and past tobacco and alcohol use. For menstruation history questions, the women questioned the quantification of menstrual flow (“On average when you had your period, how many days did you usually require a pad, a tampon, or comparable protection [during each decade of your life]?”), stating, “I don’t know how accurate it would be, number of pads. Some of us might use four pads and some might use 12, not that they needed it. Some are just like that. So the number of pads here would not help you in a study because people are so different,” and “I think that the days of the cycle would determine the number of pad-protected days.” The memory issue was resolved in the following manner. In the final survey, the question was rewritten so that women were asked about the length of their past menstrual cycles in ranges of days, rather than a specific number of days. Also in the final survey, respondents were asked whether their menstrual flow was “light, medium, heavy, or very heavy” as opposed to being asked about a specific number of pad-protected days.

Women in both age groups also had difficulty remembering the names of previously used contraceptive devices (see Figure 3). In the original survey, women were asked to describe the types of contraceptives they had used in previous decades of their lives. This issue was resolved by including names and pictures of different contraceptive devices in the final survey so that the survey respondents could select the pictures that corresponded to the ones they had used.

When questioning tobacco use, the memory issue was resolved by asking retrospective smoking-related questions beginning at ages 8–10, rather than at age 5. Thus, the time period of remembrance was shortened in the revised survey. In addition, cigarette use questions were asked in relation to cigarette packs smoked rather than the actual number of cigarettes smoked.

In addition to difficulty remembering past events, participants in the younger age group expressed difficulty in quantifying amounts of alcohol used previously. The original survey included the following statement, which was answered separately for each type of alcohol described: “During each decade of your life, how many 12 oz. bottles or cans of beer did you usually drink each week or month? (Circle to indicate if number is per week or per month).” The women in the focus groups responded by asking: “Who knows what a 4 oz. glass of wine is?” and “You could ask (instead), ‘How many bottles of beer did you have?’” This quantification problem was resolved in the final survey by quantifying alcohol consumption at each decade of life in the following manner: “How many beers/glasses of wine/mixed drinks did you usually drink in a day, a week, or month when you were _______ age?” This question was asked separately for beer, glasses of wine, and mixed drinks.

In the older age group, all the women shook their heads negatively when asked whether they would like to have the

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**RECEIVING A MAILED SURVEY REQUESTING THE PARTICIPANT’S CONTACT INFORMATION**

**18–50 Years**

Who’s gonna get this information?
You told me it’s gonna be anonymous.
If it was an anonymous questionnaire, then how would you go about asking for contact information?
Maybe if they just restated that (contact information) would be separate and no one with the survey would know (which survey I completed).

**51+ Years**

I would have a problem. I would wonder how someone would have access to my social security number.
I would be concerned.

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**CONTRACEPTIVE DEVICES USED IN THE PAST**

**18–50 Years**

When you go that far back, how do you know what your birth control pills had in them?
My birth control pills were taken off the market and I was issued a new brand.

**51+ Years**

If they used an interuterine device they may not remember.
Yeah, (they may not remember) the proper name of it.
I don’t remember any of the brands.
I do not remember.
I would have to skip that page.
This is a problem. This is a big problem.
And also, even if you remembered the brand, like Ortho-Novum, they have several different kinds.
Certain things (described in the survey) were not available to us. Like the Norplant came after I had babies.
There was a point in some of our lives where doctors told us not to use birth control pills if we were prone to cancer. I can’t say that’s the reason I had all those babies, but that’s what was told to me.
Actually, our doctors never took time to tell us, “Well your medication has this in it and this in it.”
No, they just said, “Here’s your prescription.”

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**Figure 3. Difficulty Remembering the Names of Previously Used Contraceptive Devices**

**Figure 2. Concerns About the Confidentiality of Survey Information Provided**
survey administered via telephone. Seven participants voted for a mailed survey that would be returned via postage-paid mail, and two participants voted for a face-to-face mode of administration. Another participant in the older group suggested providing study participants with a contact telephone number that they could call if they had difficulty answering a question. When questioned about their preferred mode of survey administration, women in the younger age group stated that they did not want the survey questions to be administered via home interview. The women stated, “I don’t want a home interview,” “The interviewers would really have to prove themselves coming to my home. People do so many scams,” and “I’d rather do a clinic interview.” However, two women in the younger group stated that if the interviewers called first to make an appointment with them, they would not mind participating in a home interview. Thus, a mailed survey was chosen as the final mode of administration by the staff of the larger study.

Figure 4 shows the responses of the study participants to the racial identification items on the survey. These items asked: “In which of the following categories would you classify yourself?” (Respondents could choose from White/Caucasian, Black/African American, Hispanic/Latino, Asian/Pacific Islander, Middle Eastern, Native American or American Indian, Alaskan Native/Aleut/Eskimo, or Other); “Is there an ethnic group or ancestry with which your family household identifies? (e.g., Korean, Chaldean, Puerto Rican, German, etc.)” (open-ended); “What country are most of your father’s ancestors from?” (open-ended); and “What country are most of your mother’s ancestors from?” (open-ended). As seen in Figure 4, women in the younger age group had questions about the relevance of the racial identification question to the aims of the survey. The women indicated that they were not averse to providing information related to their racial backgrounds but that they wanted to know the relevance of this information to their health. In contrast, women in the older age group questioned the relevance of parents’ country of origin to their own racial identity. To address the comments made by the focus group participants, this statement was added in the final survey: “The following questions are about your heritage, social setting, and culture. This is useful information since some diseases are more common in some ethnic or cultural groups than others.”

Women in both age groups commented on the lack of clarity of the terminology used in the survey. In particular, the term “ionizing radiation” was unclear to both groups of women. In the older age group, the term “demographic” was unclear. One participant suggested using the term “general background” instead. Thus, in the final survey, the term “ionizing radiation” was deleted and “General Background” was substituted for the term “Demographic Questions.”

Other themes that emerged from the data were age-group specific. For example, in the younger age group, the cultural relevance of the exercise items on the survey emerged as a theme. In terms of cultural relevance of the exercise questions, the women in the younger group raised questions about the types of sporting activities listed in the survey. They noted that some of the sporting activities listed, such as playing tennis, would not apply to the African Americans with whom they interacted. The study participants also suggested additional sporting activities that could be included in this list, such as dodgeball, volleyball, and jogging. In the final survey, questions were asked about physical activity at work (e.g., standing, carrying heavy loads), physical activity in the household (e.g., light cleaning), and exercise, sports, and hobby activities. In each case, the questions in the final survey used an open-ended format. Participants were asked to write the specific types of physical activity in which they engaged in each category.

In contrast, in the older age group, focus group participants indicated that because of different medical practices in previous years, their healthcare providers did not always give them the names of their birth control medications. In the final survey, brand names of previously used birth control medications were not included. Instead, the following statement was added: “For all contraceptives you have EVER used, we would like to ask you what type it was (birth control pill, shot, injection, or implant) and when you started and stopped using that particular type of contraceptive.”

**Perceptions of Breast Cancer Risk**

Figure 5 shows the responses of the study participants when they were asked to name some breast cancer risk factors. Little overlap occurred between the responses provided by participants in the two age groups, with the exception of responses to survey questions related to breast cancer risk factors. Some of the “risk factors” identified by the younger age group actually were erroneous. For example, one of the participants in this group, who happened to be a nurse, stated that lack of exposure to estrogen was a breast cancer risk factor. Also,
in response to being asked the meaning of the phrase “health risk,” women in the younger age group indicated that a “health risk” was something independent of their own behavior or actions, stating “There is something I’m taking or that I’m going to take that is going to harm me,” and “Something in the environment.” In contrast, four women in the older age group mentioned smoking as a health risk factor, and another woman in this age group discussed secondhand smoke as a risk factor.

Reported motivation to complete the survey differed according to age group. Two women in the younger age group stated that they felt completing the survey would help women in their own age group who had problems similar to their own, stating “. . . the information I would be giving the surveyors would help whatever problem I’m having, to solve it,” and “. . . helping someone else who might have a problem similar to yours.” However, two women in the older age group stated that they would complete the survey because doing so might help other women or future generations. “I would fill it out because it’s a study of women and I have two daughters who are young women now. If something should happen where this study might help with diagnosis for them, anything that will help is not going to hurt,” “Completing the survey is a benefit. I have nine daughters, so the information would help them. I have no problems with it,” and “I’d do it because as a group of women, Black women don’t tend to want to [complete a survey] for various reasons. . . . We don’t get a lot [of information] about women. . . . I just feel like that’s the only way you’re going to get [the information].”

Discussion

Health beliefs, such as perception of breast cancer risk, appear to affect cancer screening behavior (Bailey et al., 2000; Pearlman et al., 1996; Roberson, 1994; Stein et al., 1992; Womeodu & Bailey, 1996; Yancey et al., 1995). The goals of this study were to use focus group data obtained from two groups of African American women (aged 18–50 and 51 and older) to modify a breast cancer risk factor survey and to assess perceptions of breast cancer risk among the focus group participants.

In terms of research implications, this study demonstrates how focus group methods can be used to modify existing surveys to make the surveys more appropriate for the populations that will complete them. In the present study, the final survey was modified substantially to reflect the language recommended by the focus group participants. In addition, as suggested by a focus group participant, each section of the final survey was photocopied on a specific color of paper to demonstrate the distinctions among the different sections of the survey. Other suggestions made by the focus group participants to modify the survey included explaining the term “confidential,” providing a rationale for race and ethnicity items on the survey, including pictures as well as names of previously used contraceptive devices, and simplifying responses to items requiring quantification. The final survey will be pilot-tested prior to its use as part of a larger epidemiologic study.

The responses provided by the focus group participants may not be unique to African American women. That is, a group of Caucasian women or Latinas might have provided similar responses. However, the patient population of HFHS, from which

<table>
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<tr>
<th>Table 5. Breast Cancer Risk Factors</th>
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<tbody>
<tr>
<td><strong>18–50 Years</strong></td>
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<tr>
<td>Environment</td>
</tr>
<tr>
<td>Family background</td>
</tr>
<tr>
<td>Genetics</td>
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<tr>
<td>How the family took care of their health</td>
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<tr>
<td>I think diet and smoking.</td>
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<tr>
<td>Exercise</td>
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<td>Sleeping in a bra with wire in it</td>
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<tr>
<td>Sports bras</td>
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<tr>
<td>Exposure to chemicals</td>
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<td>Lack of estrogen</td>
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<td>Silicone implants</td>
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<td>Drugs</td>
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<td>Hormones</td>
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<tr>
<td>Weight</td>
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<tr>
<td>Breast density and fibroids</td>
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<tr>
<td>Different combinations of prescribed medications</td>
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</tbody>
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**51+ Years**

Heredity, diet

Hormone replacement

. . . if you have a history of breast cancer

**Discussion**

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**Table 6. Cultural Relevance of Family History Questions**

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<td>Yes, right here in the city of Detroit my great-grandmother died and on her death certificate it just says, “reasons related to old age” because she was 88.</td>
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the study participants were selected randomly, is representative of the population characteristics of southeastern Michigan. Therefore, the responses of the focus group participants likely are representative of those of other African American women of these age groups in southeastern Michigan.

The results of this study are informative for developers of instruments designed to measure breast cancer risk among African American women. The differential comments made by each age group in assessing the same breast cancer risk factor survey demonstrate that a survey needs to be both culturally and age appropriate for the population that will complete it. Also, a survey should be administered in the mode most acceptable to those who will complete it. Prior to conducting a survey, it would be helpful to discover whether potential respondents prefer mailed or telephone surveys or surveys administered face-to-face in their homes or at a central location. In the present study, researchers ascertained that administering the survey by telephone was not a mode preferred by either age group.

Each age group perceived breast cancer risk factors differently, as indicated from the results of the focus groups. Women in the younger age group gave a number of erroneous responses when identifying factors associated with breast cancer risk. In this age group, risk factors cited included wearing bras with underwires, wearing sport bras, and lack of estrogen. This lack of risk awareness could translate later into low rates of breast cancer screening among participants in this group. The younger women stated that their motivation to complete the survey stemmed from a desire to help other women in their own age group.

In contrast, women in the older age group provided more accurate descriptions of breast cancer risk factors but indicated that they did not know the cause of death of many previously deceased family members. If women do not know their family health history, they cannot be aware of all of their breast cancer risks. Members of the older age group also questioned the relevance of their parents’ countries of origin to their own breast cancer risks. These women indicated being motivated to complete the survey to help future generations of family members.

The focus group results could be used in clinical nursing practice to gain a better understanding of perceptions of breast cancer risk factors among younger and older African American women. This could lead to the development of culturally and age-appropriate nursing interventions designed to address these perceptions and enhance the likelihood of adherence to recommended mammography screening guidelines. Perhaps an effective way to facilitate mammography screening would be to begin to address perceptions of breast cancer risk factors among younger African American women so by the time they reach screening age, the risks and benefits of screening would be clear to them. A caveat is that addressing perceptions of breast cancer risk factors alone is less likely to facilitate screening than if other factors, such as the cost of breast cancer screening, transportation, and childcare issues related to screening, also were addressed. These factors may hinder adherence to breast cancer screening regardless of the manner in which women perceive their breast cancer risk.

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References

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For more information...

- National Institutes of Health Breast Cancer Home Page  
  www.nci.nih.gov/cancer_information/cancer_type/breast

- Medline Plus: African American Health  

*These Web sites are provided for information only. The hosts are responsible for their own content and availability. Links can be found using ONS Online at www.ons.org.*