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Education strategies are needed for women interested in genetic testing for inherited susceptibility to breast cancer, but who are at low to moderate risk based on family history. This project was designed to develop and test appropriate and effective education and counseling measures for women from differnt ethnic groups at low to moderate risk. The project includes the use of questionnares, focus groups and a randomized control trial of education strategies to determine the most effective and appropriate measures for use with low-to-moderate risk women from minority populations. Resulting strategies will be usefully applied in the large, ethnically and economically diverse populations of health maintenance organizations from which increasing numbers of women receive health-related information and care. During the second year of the project, the mailed survey of family history and attitudes towards genetic testing has been complted in a sample of African-American, Latina, Asian and white women, and a phone survey of non-responders is ongoing. Focus groups and analysis of questionnaire data are ongoing.

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Catherine Schaf 9-28-98

PI - Signature Date

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Introduction

To date, there has been little research on appropriate education strategies for women interested in testing for inherited susceptibility to breast cancer, but who are at low to moderate risk based on family history of cancer. Information about interest in and attitudes toward testing is especially scarce for women from minority populations and those of lower socioeconomic status. This project was designed to develop and test appropriate and effective education and counseling measures for women from different ethnic groups at low to moderate risk. The project includes the following elements: 1) A survey of the prevalence of knowledge, attitudes, and intentions with regard to testing for inherited susceptibility to breast cancer among a racially and ethnically diverse stratified random sample of 16,795 women within the well-defined population served by Kaiser Permanente Medical Care Program (KPMCP). 2) Focus groups will be used to further explore and define possible ethnic group differences in attitudes toward genetic testing. 3) Results of focus groups and initial questionnaire will be used to refine and extend information collected from an ethnically-stratified sample of 1,200 African American, Latina, Asian, and white women at low to moderate risk (based on family history) 4) A randomized controlled trial will be conducted to compare educational strategies. The trial will include 600 women, with equal numbers of African American, Asian, Latina, and white women in each arm.

Body

During the second year of the study a short questionnaire was mailed to a probability sample of 16,795 women drawn from 386,123 geocoded women health plan members. Information on race and ethnicity is not routinely available for all health plan members, so in order to draw an ethnically balanced sample, home addresses for women health plan members ages 25-70 years were geocoded by 1990 Census block. These codes were linked to data on the representation of specific ethnic groups in each census block. The sample was designed to have equal representation of the four race/ethnic groups under study, and allowed for predicted response rates to the questionnaire (estimated at 50%). Data obtained in the questionnaire include personal and family history of breast and ovarian cancer, screening practices, knowledge of and attitudes toward inherited susceptibility for breast or ovarian cancer, testing for same, and sociodemographic information including ethnicity, religion, education, and occupation.

The short questionnaire was sent to the selected sample of women, and a follow-up mailing was sent to non-responders. In all, 6972 (42%) women responded to the mailed questionnaire. In order to augment this disappointing response, as well as to assess non-responder bias we are conducting a brief phone interview (Appendix 1) with 3500 women selected from the non-respondents.

All the returned short questionnaires have been data entered, and we have preliminary data which indicate that our sampling strategy was effective in drawing an ethnically balanced sample. Of the women who returned the survey 17% were African American, 19% were Asian, 16% were Hispanic and 48% were white.

We have begun to conduct focus groups to gather information that will inform both the extended questionnaire and the design of the education strategies. Subsamples of survey respondents are being selected to constitute these focus groups. We will conduct a total of eight ethnic-specific focus groups, two groups each for women who self-identify as African American, Asian, Hispanic or white. Focus group meetings are about two hours long, and collect information from a small group of women, according to a prescribed agenda (Appendix 2) about their knowledge and opinions about breast cancer in general and about inherited susceptibility and genetic testing in particular.

Work has begun on the development of the extended questionnaire. In consultation with Drs. Beth Newman and Caryn Lerman, we have continued to gather relevant materials and questionnaires used in other studies. The extended questionnaire will obtain information on non-genetic risk factors for breast and ovarian cancers, knowledge of and attitudes toward risk associated with ethnic group membership and age, screening history and behavior, detailed questions concerning attitudes toward cancer, its prevention and treatment, as well as more detailed questions concerning attitudes toward inherited susceptibility to cancer and preferences regarding information about testing for inherited susceptibility. The questionnaire will also included brief, standardized measures of psychological and physical functioning, social networks and support, and general health status.

In the trial, we plan to compare educational strategies and educational materials as the means for delivering information about testing for inherited susceptibility to breast and ovarian cancers. These approaches will be modified based on results from the mailed surveys and phone interviews and the feasibility of various approaches within the health plan setting at the time in of the intervention. Cultural tailoring of the educational message will be incorporated into the interventions. The effectiveness of the educational approaches will be judged by outcomes that include knowledge and intentions toward genetic testing and screening behavior, client satisfaction, costs of the intervention, and utilization of medical services.

Work in progress: We are conducting focus groups, analyzing data from the mailed questionnaire, conducting CATI interviews with non-responders to the mailed questionnaire, and are continuing design of the extended questionnaire and the interventions.

Conclusions:
None yet

References:
None

Appendix 1

KAISER BREAST CANCER SURVEY
March 18, 1998

PURPOSE

The purpose of this survey is to help us understand how women think about breast cancer, and how their experiences affect those thoughts. There are no right or wrong answers to these questions; please just report what best describes your situation. Your responses to these questions will be kept completely confidential. They will not become a part of your medical record. Your participation or refusal will not alter your relationship with Kaiser Permanente in any way. May I continue?

1. Yes
2. No (END INTERVIEW)

PREFER

1. Do you prefer to read or speak a language other than English?

1. Yes
2. No (GO TO BIRTHDAY)
7. DK (GO TO BIRTHDAY)
9. RF (GO TO BIRTHDAY)

LANGUAGE

1a. Which language do you prefer to speak?

1. Spanish
2. Cantonese
3. Mandarin
4. Tagalog
5. Japanese
6. Other (specify)

REGRET

1b. I am sorry we have not translated these questions into (preferred language). Would you be willing to answer these questions in English?

1. Yes
2. No (GO TO CLOSING)

BIRTHDAY

2. What is your date of birth? __/__/__
mm dd yy

7. DK
9. RF

GENHLTH

3. Compared to other women your age, would you say your health is:

1. Poor
2. Fair
3. Good
4. Very Good, or
5. Excellent
7. DK
9. RF

The next few questions are related to breast cancer and ask for your thoughts and opinions. Remember there are no right or wrong answers; we are interested in your opinion.

FREQ_GET

4. How frequently do you think about getting breast cancer?

1. Never
2. Rarely
3. Sometimes
4. Often
5. All the time
7. DK
9. RF

OTHRHLTH

5. Compared to other health problems or diseases, how much do you worry about getting breast cancer?

1. Not at all
2 A little bit
3. Some
4. Quite a bit
5. A great deal
7. DK
9. RF

OPINION

6. In your opinion, is there too much, too little or just the right amount of attention to breast cancer in the media, such as TV, magazines or newspapers? Would you say...

1. There is too much attention
2. The amount of attention is about right
3. There is too little attention
7. DK
9. RF

The following questions are about breast and ovarian cancer in members of your family. Please include information about all of your blood relatives, even if they are no longer living, but do not include family members who are adopted or married into the family.

HAVERELS

7. Do you have any relatives who have ever been diagnosed with breast cancer?

1. Yes
2. No (GO TO ANYRELS)
7. DK (GO TO ANYRELS)
9. RF (GO TO ANYRELS)

RELWHO

7a. Which relatives? Read and select all that apply.

1. Mother
2. Sisters
3. Half-sisters
4. Paternal Aunts
5. Maternal Aunts
6. Maternal Grandmother
7. Paternal Grandmother
8. Cousins
9. Other

ANYRELS

8. Do you have any relatives who have ever been diagnosed with ovarian cancer?

1. Yes
2. No (GO TO HLTHPRO)
7. DK (GO TO HLTHPRO)
9. RF (GO TO HLTHPRO)

WHATRELS

8a. Which relatives? Read and select all that apply.

1. Mother
2. Sisters
3. Half-sisters
4. Paternal Aunts
5. Maternal Aunts
6. Maternal Grandmother
7. Paternal Grandmother
8. Cousins
9. Other
77. DK
99. RF

Ask if either HAVERELS = 1 or ANYRELS = 1, otherwise go to FRIENDS

HLTHPRO

9. Have you ever spoken with a health care professional about your family history of breast or ovarian cancer?

1. Yes
2. No (GO TO FRIENDS)
7. DK (GO TO FRIENDS)
9. RF (GO TO FRIENDS)

WHOPRO

9a. Who did you speak with?

1. Primary Care Provider
2. Geneticist/Genetic Counselor
3. Nurse Practitioner
4. Obstetrician/Gynecologist
5. Other (specify)
7. DK
9. RF

FRIENDS

10. Have any of your close friends been diagnosed with breast or ovarian cancer? (If yes: Probe for which type.)

1. No
2. Yes, breast cancer
3. Yes, ovarian cancer
4. Yes, both
5. Other
7. DK
9. RF

Scientists have recently discovered that some cases of breast cancer are caused by genes that are passed from one generation to the next. These genes may increase the chance that a woman will develop breast or ovarian cancer sometime in her life. Genetic testing using a blood sample is now available in some places.

GENTEST

11. How much have you read or heard about genetic testing for breast cancer?

1. Nothing\Almost nothing
2. Relatively little
3. A fair amount
4. A lot
7. DK
9. RF

LEARNTST

12. If you wanted to learn more about genetic testing for breast cancer, which of the following ways would you prefer to learn more? Read and mark all that apply.

1. Brochure or pamphlet you could read
2. One-on-one talk with a health care professional
3. A videotape you could take home
4. A group discussion with a health care professional
5. A family visit with a health care professional
→ 7. Don't want to know more
77. DK
99. RF

BLOODTST

13. If a blood test could tell you if you carried a gene that affected your chances of getting breast cancer, would you be interested in taking that test?

1. Yes
2. No (GO TO DOTALK)
7. DK (GO TO DOTALK)
9. RF (GO TO DOTALK)

CHANCES

13a. If the blood test could tell you about your chances of getting breast cancer, but if you could not prevent it, would you still be interested in taking the test?

1. Yes
2. No
7. DK
9. RF

DOTALK

14. Besides talking to their doctors, women may talk to other people about their health care. Do you talk to anyone, besides your doctor, about your health?

1. Yes
2. No (GO TO HAVEXAM)
7. DK (GO TO HAVEXAM)
9. RF (GO TO HAVEXAM)

WHOTALK

14a. From the following list, who do you usually talk to when you are making decisions about your health? Enter all that apply

1. Your friends
2. Your sisters or brothers
3. Your children
4. Your husband or partner
5. A religious or spiritual advisor
6. Your parents
7. A counselor or therapist
8. Anyone else?
77. DK
99. RF

These next questions ask about health practices:

HAVEXAM

15. During the past two years, how many times did a physician or other health care professional conduct a breast exam on you?

1. Never
2. Once
3. Twice
4. Three or more times
5. Didn't see a physician
7. DK
9. RF

DOEXAM

16. **During the past two years, did you do a breast exam on yourself? (That is, have you ever felt your own breast the way a doctor or nurse does to look for lumps or changes?)**

(Interviewer: If respondent had both breasts removed, enter NA)

1. Yes
2. No (GO TO MAMMO)
7. DK (GO TO MAMMO)
9. RF (GO TO MAMMO)
8. NA (Go to MAMMO)

OFTENBE

16a. How often did you conduct a breast exam on yourself in the last two years? Would you say...

1. Less than once a year
2. A few times a year
3. About once a month
4. More often than once a month
7. DK
9. RF

MAMMO

17. A mammogram is an x-ray of the breast taken by a machine that presses against the breast while the picture is taken. Have you ever had one?

1. Yes
2. No (GO TO BIOPSY)
7. DK (GO TO BIOPSY)
9. RF (GO TO BIOPSY)

HADMAM

17a. About how long has it been since you had your last mammogram?

1. 1 year ago or less
2. Between 1-2 years ago
3. More than 2 years ago
7. DK
9. RF

WHYMAM

18. Women have mammograms either because of a problem, like a lump, or for a checkup. What was the reason for your last mammogram? Would you say it was for...

1. A problem (such as a lump, pain or discharge) or
2. A check-up
7. DK
9. RF

BIOPSY

19. Have you ever had a breast biopsy? (Please include surgical and needle biopsies as well as needle aspirations.)

1. Yes
2. No (GO TO DR_TELL)
7. DK (GO TO DR_TELL)
9. RF (GO TO DR_TELL)

HOWMANY

19a. How many biopsies have you had? _____

7. DK
9. RF

DR_TELL

20. Have you ever been told by a doctor that you had breast or ovarian cancer?

1. Yes
2. No (GO TO MARITAL)
7. DK (GO TO MARITAL)
9. RF (GO TO MARITAL)

WHATTOLD

20a. Were you told that you had breast cancer, ovarian cancer, or both?

1. Breast cancer
2. Ovarian cancer
3. Both
7. DK (GO TO MARITAL)
9. RF (GO TO MARITAL)

AGE

20b. How old were you when you were first diagnosed? Enter age first told had cancer.

_____ ____YRS

7. DK
9. RF

These last few questions ask for a little background information about you.

MARITAL

21. What is your current marital status?

1. Single, never married
2. Married or living as married
3. Separated or divorced
4. Widowed
7. DK
9. RF

RACE

22. What is your race/ethnicity? Enter all that apply.

1. White
2. Black/African-American
3. Hispanic/Latina
4. Chinese
5. Japanese
6. Other Asian
7. Pacific Islander
8. Native American
9. Other (specify____RACETXT)

77. DK
99. RF

EDUCA

23. What is the highest grade that you completed in school?

1. Did not go to school
2. Grade school (K-8)
3. High school-did not graduate (9-11)
4. High school graduate (12)
5. Some college or technical school
6. College graduate
7. Graduate or professional school

77. DK
99. RF

CONTACT

24. This survey is part of a study to determine what women think about breast cancer and testing for inherited risk. We will be inviting some of the women who have completed this survey to take part in other aspects of the study. May we contact you to tell you more about the study?

1. Yes
2. No

Many thanks for taking the time to complete this survey!

Educational Interventions for Women Interested in Genetic Testing For Inherited Susceptibility to Breast and Ovarian Cancer

FOCUS GROUP AGENDA

I. Introduction and Explanation of Focus Group Process

Greet participants, have them sign in with their names and addresses on a 4x6 card. Cards will serve as a record of attendance. Names and addresses will facilitate mailing checks.

Introduce moderators, purpose of the focus group, and what tasks will be accomplished. Moderator: Emphasize that in this session we are not looking for "RIGHT" or "WRONG" answers, because there are no right or wrong answers. Emphasize that what is most important is what you really think:

> "Say the way it is for you. Please remember that people see things differently and it is fine if someone says something different than you or if you think about something in another way. All ideas and points of view are welcomed and respected. No put downs here".

Ask if there are any questions.

Voluntary and confidential. Inform women that they can discontinue their participation at any time. Explain the reason for recording, ask that everyone use only first names, assure the participants that no one's name will appear in any publication, report or medical record. Information is for research purposes; it will be kept confidential, and will not be shared with physicians or other Kaiser Permanente personnel.

Any questions?

II. Introduction of Group

Moderator introduces herself, and asks each person to say her first name and tell the group something about herself, such as why she decided to attend the session.

III. Introduction of Topic

Moderator: Today, we are going to be talking about breast cancer, families, and testing for breast cancer genes. It can be difficult to talk about these things, but it is important to learn what women think about these things so that we can educate and help women with the information they want and need.

Let's begin our discussion by talking about breast cancer.

1. **"How much is breast cancer on your mind?"** Those of you who don't think about it much, why is that?

2. **Speaking of families, if your grandmother and one of your aunts had had breast cancer, do you think you would know about it? How much do you know about your family's history of breast cancer? Would this information be discussed and shared in your family?**

3. **"Compared to other women, do you think your chances of getting breast cancer are higher or lower than average? " Why?** What kind of things have you done or not done because you believed

your chances were higher or lower than average?

IV. Explanation and Discussion of Inherited Susceptibility to Breast Cancer
Moderator: Now I'm going to tell you a little more about genes and about breast cancer in families, and then ask for your opinions about some of the issues.

Humans have lots of genes. There are genes for hair color, skin color, and almost all the physical features we are born with. Genes are passed from parents to children, generation after generation, which is the reason that family members may share certain features such as curly hair, or long fingers, or a nose that has a certain shape, which make them look like members of the same family.

There are some diseases which run in families, too. In the same way that a large nose or small feet might be passed from parent to child, so can the tendency to develop a disease. In a small number of cases, breast cancer can be one of these diseases.

[Use family tree picture here]

Let me show you a picture that may help explain what I am talking about. This is an example of a woman's family tree. This picture shows 3 generations of this family. In this family, the grandmother has had breast cancer, and 2 of her daughters have had breast cancer – the sisters of this woman's father. Even though men very rarely get breast cancer themselves, they can pass the genes on to their daughters who can get breast cancer, as you can see in this example. The tendency to develop breast cancer in this family is passed from generation to generation. This is what we mean by having a family history of breast cancer. Even in this kind of family, however, not everyone will have the genes and not everyone will get breast cancer.

Most cases of breast cancer are caused by other factors, most of which we do not know. Only a small number of cases of breast cancer are caused by these genes, which only occur in some families.

Does anyone have questions about the information? (If participants have questions about their personal situation or family history, gently tell them you cannot answer these sorts of questions. You can only clarify the information that was presented. Ask them to write down their questions and you will refer them to someone who can answer their questions at the end of the group).

4. In the information I just told you, did you hear anything completely new that you hadn't heard before? Did you hear anything that shocked or upset you?

5. If your mother and your aunt both had breast cancer, would you feel like your chances of getting breast cancer were high?

6. Would you want to know if cancer in your family was caused by genes? Why or why not? If your family had genes that caused cancer in the family, would you want to keep the information private from people outside your family? Why?

V. Genetic Testing for Inherited Susceptibility to Breast Cancer
Moderator: "Now I'm going to tell you a little about a test for the genes that cause breast cancer, what

the test means, and then discuss some of the advantages and disadvantages of being tested.

There is a blood test that can be used to look for the genes that cause breast cancer in some families. If several members of a family have had breast cancer, it is possible to use this test to see if certain genes are causing breast cancer in the family, and to see who in the family has the gene. Before a woman can take the blood test, she must meet with a genetic counselor who explains the test and the advantages and disadvantages. If a woman then decides to take the test, the result can be positive or negative.

If the blood test is positive and a woman **does have** the genes, it tells her that her chances of getting breast cancer are pretty high, but it cannot tell her for sure that she will get breast cancer. A positive test means that other members of her family probably have the gene, too, and that it is possible for her to pass on the gene to her children. If a woman has already had breast cancer, a positive test may explain why she got breast cancer, and it can tell her that her chances of getting breast cancer in her other breast are pretty high.

If the test is negative – a woman has **not** inherited the gene - it can tell her that her chances of getting breast cancer are average – the same as other women her age and with similar background. A negative test cannot guarantee a woman that she will not get breast cancer because other things besides these genes cause cancer. Does anyone have any questions?

If the test is positive, there is no way to change the gene, but there are some things that a woman with a positive test can do, such as increase her efforts to detect breast cancer early by having more frequent mammograms, having breast examinations by a doctor, and examining her own breasts.

7. Of course we are not offering any testing as part of this project, but do you think you would you be interested in taking this test, based on what you know right now? Why or why not.

8. In your opinion, what would be the advantages and disadvantages in taking the blood test for breast cancer genes?

[Moderator makes separate lists on large sheets of white paper.]

(If it hasn't come up: You could reduce your risk of getting breast cancer by having surgery to remove your breasts.)

9. Should family members discuss being tested with the rest of the family, or should it be a private decision for each family member? Do you think that all members of a family should decide the same way, that is, all members decide to have the test or all members decide not to have it? What might happen if family members disagree about taking the test?

[10. What do you think about genetic testing for a young woman or girl? How do you think the knowledge that she has a high chance of getting breast cancer would change her life?]

11. If you had a positive test, what, if anything would you do? What's the first thing that comes to mind? **What, if anything, would you do if you had a negative test?** What's the first thing that comes

to mind?

12. What do you think about a woman with a positive test who decides to have her breasts surgically removed to prevent breast cancer?

13. Do you think a woman should do things to try to reduce her risk of cancer, or should it be left up to fate or to God?

VI. Consequences and Implications of Genetic Testing for Breast Cancer

Let's talk a little bit about how the test might affect different people.

14. Would you worry about employers or health insurance companies knowing the results if you were interested in taking this test? Would it change your mind about the test?

VI. Kaiser Permanente and Genetic Testing

Moderator: Let's switch a little and talk about genetic testing in Kaiser Permanente.

15. How would you prefer to learn about genetic testing and breast cancer genes? Would you come to class or a group discussion? Would you want to bring family members with you? Would you prefer a video to take home that you could watch by yourself or with other members of your family? Should Kaiser send something to read in the mail or have brochures in the waiting room?

VII. Closing the Group

Ask if there are any final questions. Thank everyone for their participation.