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13. ABSTRACT (Maximum 200) <p style="margin-left: 40px;">The purpose of this project is to develop methods to encourage earlier detection of breast cancer in rural African-Americans. Our focus is on cultural and psychosocial beliefs which contribute to patient delay in seeking treatment for the symptoms of breast cancer</p> <p style="margin-left: 40px;">A documentary video and other educational materials are being developed which will be utilized in several aspects of the intervention. The components of the intervention include a health conference, media campaign, community educational programs, and information provided to younger patients to share with their older female relatives.</p> <p style="margin-left: 40px;">The pre-intervention census survey of the two counties is almost complete and the instrument for the pre-intervention interviews has been developed. Once it is pre-tested, the data collection will begin. This will be followed by the intervention on the experimental county which is scheduled to begin in early 1998.</p>			
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FOREWORD

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Donald R. Lammie 9/29/97
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Introduction:

The goal of this project is to develop methods to encourage earlier detection of breast cancer in rural African-Americans. Our previous research has indicated two reasons for late stage breast cancer presentation in this population: 1) lack of breast screening including clinical breast exam and mammography, and 2) patient delay due to cultural and psychosocial beliefs.

The current research seeks to ascertain when these beliefs are formed and test whether they can be modified. Through an extensive educational intervention, we will determine if changing these beliefs increases rates of screening behavior and decreases delay in seeking medical care for breast symptoms.

Body:

The experimental design involves community-wide, in depth surveys of women ages 19 and over in two similar counties, Pitt and Wilson. These interviews will be performed before and after the educational intervention which will be conducted only in the experimental county, Pitt County.

There are four components of the intervention: 1) a conference on minority health issues for the local community, 2) a media campaign, 3) educational programs in churches, schools, and businesses, and 4) an intervention with younger women during their Ob-Gyn appointments counseling them to take information to their older female relatives. Each of these components is in the developmental stage at this time.

In preparation for the intervention, we have produced a documentary video featuring several patients from the East Carolina University (ECU) Breast Clinic. These patients were followed during their diagnosis and treatment procedures and filmed in their homes and at their churches. They freely discussed their fears, beliefs, and concerns related to barriers in breast cancer treatment. The video will be utilized in several aspects of the intervention including the health conference, educational programs, and media campaign.

We have expanded the theoretical framework to include the Health Belief Model as discussed by Rosenstock (1). The basic assumption of this model which has been applied to cancer screening behavior is that the individual is susceptible to external influence such that one's perception of susceptibility to and severity of (perceived threat of disease), in this case, breast cancer, is influenced by demographic and psychosocial variables (2). It follows that cues to preventive actions develop from mass media, advice from family and friends, and previous experience of illness affecting family and friends (3). Individual health choices to follow recommended preventive health action (e.g., screening) are determined by the perceived benefits of that action minus its perceived barriers (including financial, time and information factors). Under this model, individuals choose those actions where the perceived benefits are greater than the perceived barriers (3).

The intervention will provide the external cues to action in the mass media campaign, advice from younger relatives, and information from educational programs. The goal is to increase breast cancer screening behaviors and knowledge by amplifying the perceived benefits and reducing the perceived barriers through education.

In the first year, several tasks in the Statement of Work have been accomplished. Regarding Task 1, the project manager and health educator have been hired and the Advisory Board has been assembled. Several meetings of the Advisory Board have lead to formulation of strategies which should be effective in reaching this community.

The second task, conducting the pre-intervention survey, is well underway. Twenty interviewers have been recruited and trained. The household survey to determine the sampling frame is almost complete and data for approximately 1700 women have been entered into the computer, cleaned, and verified. These data will then be used to select the experimental and control populations who will be interviewed. The interviewers will come from the pool of census surveyors and will receive additional training for this particular questionnaire.

The instrument has been developed and is in the process of being pre-tested and revised (attached in appendix). One time-saving factor involves using the Teleform software for developing our survey instrument. This is labor-intensive to format and has slowed development of the instrument. However it has the distinct advantage of being readily scanned into the computer and immediately translated into SPSS and, in the long run, will speed data analysis. Once the instrument has been pre-tested, final revisions will be made, and the pre-intervention data will be collected.

The educational materials are being developed as in Task 3. As mentioned earlier, the breast cancer video has been produced and will be used along with other educational materials for the intervention. The educational pamphlets for use in Ob-Gyn offices and advertisements for mass media are under development and will be tested and revised over the next several months.

The intervention itself (Task 4) is scheduled to begin in early 1998. With the current reliable and motivated pool of interviewers, the pre-intervention data collection should proceed expeditiously so the intervention can begin immediately upon its completion. Plans are being formulated for the conference on minority health issues for medical and community leaders which will serve as the "kick-off" for the intervention. Once underway, this should proceed without interruption or delay to allow us to approach the proposed time frame.

At this point, problems in accomplishing the proposed tasks have mainly involved personnel. In each county census workers were trained and given assignments. However, for a variety of reasons (e.g., re-location, procurement of full time employment, family illness), surveyors have resigned resulting in delays due to re-assigning the census areas. We have now assembled a dependable staff and few additional changes are expected.

Conclusions:

We hope to reduce breast cancer mortality by preventing avoidable mortality through an educational intervention with the ultimate goal of diagnosing the disease at an earlier, more treatable stage. The aspirations of this study include: 1) developing educational messages about early detection of breast cancer consistent with prevailing cultural beliefs and attitudes and 2) providing awareness of breast cancer symptoms and screening practices in conjunction with culturally sensitive methods encouraging women to utilize available resources for early detection.

If the results of this study indicate psychosocial variables are amenable to change and this is shown to affect screening behavior and ultimately disease stage presentation, it could have a major impact on breast cancer mortality. Both the approach and the findings from this study are applicable to a larger population beyond this region.

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1) Publications

The Influence of Socioeconomic and Cultural Factors on Racial Differences in Late Stage Presentation of Breast Cancer in Rural North Carolina, submitted.

2) Abstracts

Delay in Seeking Medical Treatment for the Symptoms of Breast Cancer in African-American and White Women, presentation, Society of Clinical Research Associates (SOCRA), Sixth Annual Conference, September, 1997, Colorado Springs.

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APPENDIX



Draft

14. Have you ever visited with any of the following types of health care providers or been to any of the following centers or programs for health care?

{INTER: fill in circles for all the R. Mentions}

- Chiropractor Root doctor
- Accupuncturist Biofeedback center
- Herbalist Fortune teller or psychic
- Health food store Self-help group
- Massage therapist Commercial weight loss program
- Homeopath Hypnotist
- Religious healer

Now, let's talk about your attitude about your own health.

15. Some people go to the doctor right away, whenever they're worried about their health. Others put off going even when they have a serious problem. Do you usually:

- go to the doctor as soon as you think something is wrong
- wait a while and try taking care of the problem yourself
- wait a while and do nothing to see if it will go away
- or do you usually not go to the doctor at all
- (S.C. depends on the type of problem)

Perceived Risk. Now let's talk about how worried you are about your risk for developing breast cancer.

16. Do you think it is likely or unlikely that you will get breast cancer in your lifetime?

- Very unlikely Somewhat unlikely Somewhat likely Very likely Don't know

17. Compared to most women your age, what do you think the chances are that you will get breast cancer someday? Do you think your chances are:

- Much lower Somewhat lower Somewhat higher Much higher Don't know

18. Overall, how worried are you about the chance that you might get breast cancer someday. Would you say that you are:

- Not worried at all Somewhat worried Very worried Don't know

19. Can you tell me how old you were when you had your first menstrual period? Were you:

- younger than 12 age 12-13 age 14 or older

20. Have you given birth to any children (count only children born alive):

- Yes No (SKIP to 23)

21. Can you tell me how old you were when you had your first live birth (count only your first child born alive):

- Younger than 20 Between 20 and 24 years old Between 25-29 years old 30 years or older

22. Has any doctor ever told you that you had a lump or tumor in your breast?

{INTER: If R. says that she thinks she has one now, be sure at the end of the interview to recommend that she sees a doctor/nurse}

- Yes No (S.C. not sure)

23. Have you ever had a breast biopsy?

- Yes No(SKIP to 27) (S.C. not sure)

24. How many breast biopsies have you had?

25. Did any of them turn out to be cancer?

- Yes No(SKIP to 27) (S.C. not sure)

26. Thank you for answering my questions up to now. Some of them may have been a bit hard for you. Would you be willing to tell me a bit more about how your breast cancer was first found and about any doctor or hospital visits you had after?

Family History. *Now I would like to ask you a few questions about any of your blood relatives who have had an actual diagnosis of breast cancer. Remember, we are talking about your blood relatives only and not people who are adoptive relatives or who are related to you only by marriage.*

27. How many of your blood relatives have had breast cancer?

Mother Yes No Don't know

Sister(s) Yes No Don't know # positive

Daughter(s) Yes No Don't know # positive

Grandmothers Yes No Don't know # positive

Aunts Yes No Don't know # positive

Cousins Yes No Don't know # positive

28. Risk Factors. *Women believe that different things increase their risk of getting breast cancer. Please tell me whether you think these are always, sometimes, or never risks for developing breast cancer.*

	<u>Always</u>	<u>Sometimes</u>	<u>Never</u>
Would getting your period early, say before age 12, increase a woman's chances of getting breast cancer? Would you say always, sometimes or never?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would eating a high fat diet increase a woman's chances of getting breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How about drinking more than 2 alcoholic drinks a day?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How about having breast implants?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How about having a family history of breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How about smoking regularly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How about getting a bump or a bruise on the breast. Would you say that would always, sometimes, or never increase a woman's chance of getting breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How about drinking a lot of caffeinated beverages?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Always Sometimes Never

- How about waiting to have children until you are over age 30?
- How about taking birth control pills?
- How about breastfeeding your children?
- How about going through menopause late in life, after age 55. Would you say that would always, sometimes or never increase a woman's chance of getting breast cancer?
- How about excessive fondling of the breasts?
- How about having fibrocystic disease?
- How about being older than age 50. Would you say that always, sometimes or never increases a woman's chance of developing breast cancer?
- How about never having had any children?
- How about having had cancer before. Would you say that would always, sometimes or never increase a woman's chance of getting breast cancer?

Screening. Now let's talk about the things that you may have done to protect yourself against breast cancer.

- 29. Has a doctor or other medical professional ever shown you how to examine your breasts for knots or lumps?
 Yes No Not sure
- 30. Have you ever felt your own breasts in the way a doctor or nurse does to check for knots or lumps?
 Yes No (**SKIP to 31**) Not sure

IF YES, about how often do you check your own breasts? Would you say:

- Every day
 - Several times a week
 - Several times a month
 - Once a month
 - A few times a year
 - Almost never
- (**SKIP to 32**)

- 31. Why don't you check your own breasts? Is it because:

(**INTER: fill in all that apply**)

- You don't know how
- You are embarrassed to do it
- You're not really worried about knots or lumps
- You don't think you would be able to feel a lump if there was one
- You would rather not know if there is a problem
- You lack privacy to do it regularly
- You are too young to start doing it now
- You are too old to have to worry about that now
- You forget



Draft

32. A mammogram is a picture of the breast tissue made by compressing the breast while the picture, a type of x-ray, is taken. --have you ever heard of a mammogram?

- Yes No (S.C. Not sure)

33. Have you ever had a mammogram?

- Yes (SKIP to 35) No (S.C. Not sure)

34. Why do you think that you haven't had one? (Record R's exact words--then skip to 40)

Empty box for recording exact words.

35. When was your last mammogram?

- Wast it more than three years ago Within the past three years Within the past two years Within the past year

36. What was the main reason why you decided to have your last mammogram. Was it because:

- Your doctor or nurse recommended it
You thought you might have a breast problem
You were worried about your chances of getting breast cancer
It is recommended for women of your age to have one
Someone other than your doctor or nurse encouraged you to do it
Saw a program on TV
Heard a talk at church or club
Younger relative encouraged me to do it

37. Have you ever had a mammogram that showed that something was wrong with your breasts?

- Yes No (SKIP to 40)

38. Did you have a biopsy of your breast to find out what was wrong on the mammogram?

- Yes No

39. Have you ever had any problem with your breasts that you put off seeing a doctor or nurse about?

- No Yes IF YES, can you tell me more about the problem and what you did?

BREAST CANCER OPINIONS.

40. Now I would like to ask you some questions about what you know or have heard about breast cancer. There are no right or wrong answers. I am interested in what your opinion is about whether these statements are true or false.

Table with 3 columns: True, False, Don't know. Rows include statements about breast cancer prevalence, spread, mastectomy, growth rate, and lifetime risk.



Draft

True False Don't know

- You can catch cancer from other people. True False Don't know
- Lumpectomy is a type of surgery for breast cancer in which the cancer itself but not the whole breast is removed. True False Don't know
- African-Americans with breast cancer face more than twice the risk of dying from the disease when compared with white Americans. True False Don't know
- Chemotherapy is the use of drugs to kill cancerous cells. True False Don't know
- Breast cancer tends to run in families. True False Don't know
- If a woman finds a knot or lump, it is better to do nothing because by then it will be too late. True False Don't know
- More than half of the patients treated by radiation or chemotherapy never experience nausea or vomiting. True False Don't know
- A cancer in the breast that is not treated can lead to death. True False Don't know
- Most women who get breast cancer lose their breasts. True False Don't know
- If a breast cancer is operated on, it can be stopped from getting any bigger. True False Don't know
- Finding a mass in the breast is not as serious as finding a knot or lump. True False Don't know
- Men can also develop breast cancer. True False Don't know
- As long as a knot or lump doesn't hurt, then it is not cancer. True False Don't know
- The National Cancer Institute recommends that women ages 50 and over have a mammogram every year. True False Don't know
- Women with many risk factors are certain to get cancer. True False Don't know
- A breast cancer is very curable if it is found early. True False Don't know
- Some women have a greater chance of getting breast cancer than others. True False Don't know
- A woman who has breast cancer will never again lead a normal life. True False Don't know
- If a woman finds a knot or lump, the worst that can happen is surgery. True False Don't know

BREAST LUMP ACTIONS. We are trying to find out what women would do if they found a lump or knot in their breasts. Different women have told us that they would do these things. How likely would you be to do these?

41. Would you:

<u>Action</u>	<u>Very likely</u>	<u>Likely</u>	<u>(S.C. Don't know)</u>	<u>Not likely</u>
a. Wait to see if it becomes painful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Get a mammogram	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. See a doctor for a breast exam	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Wait to see if it gets bigger	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Ask a close friend or relative for advice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Pray to God about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Watch it every day for a while to see if it changes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Ignore it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

42. Now I'd like to know which actions you think are most important. Which would you do: (enter the letter of choice)

1st action ___ 2nd action ___ 3rd action ___

RELATIONSHIPS. Now I would like to ask you a few questions about the people you have known and have around you to talk with and help you with health problems.

43. Have you ever known someone personally who has had breast cancer? Yes No (S.C. Not sure)

IF YES, what do you most remember about that person and her experiences?

(INTER: Record R's responses exactly)

Empty box with three horizontal lines for recording responses.

44. If you had a serious health problem, what one person, other than your doctor or God, would you turn to first for advice? **(INTER: Be sure to record the relationship to the person in the box as well- ie. sister, mother, male friend, and be as specific as possible.**

Empty grid box for recording relationship details.

45. Now I would like to ask you if you agree or disagree with some statements about relationships and breast cancer. There are no right or wrong answers. We are interested in your opinions about these statements that others have made.

Table with 3 columns: Agree, Disagree, Not sure. Rows contain various statements about relationships and breast cancer for which respondents can select an option.

- The strength of my own faith in God would determine if my cancer is cured.
- My prayer alone would do nothing to cure my cancer.
- I would want my church members to come to the hospital to pray with me.
- My church members praying for me in church would help to cure my cancer.
- There would be a special ceremony for me in my church to cure my cancer.
- I would not tell anyone in my church about my cancer.
- I would not think about people in church praying for me.

BELIEFS ABOUT CANCER.

53. *I just have a few more questions for you. These next items are some of the things different women have told us they believe about cancer. We are interested in your opinions. Please tell us if you strongly agree, agree somewhat, disagree somewhat or strongly disagree with the following statements. Remember, there are no right wrong answers- we just want your opinion.*

- If a cancer is cut open in surgery, it will grow faster.
- Negative feelings can cause cancer.
- If a person has cancer, there is no sense trying to do anything about it.
- People who take good care of themselves usually don't get cancer.
- A person with high blood is more likely to get cancer than a person with normal blood.
- Vaccinations weaken the immune system which can lead to cancer.
- Luck plays a big part in determining who gets cancer.
- It is better to die whole than to let a doctor cut on your body.
- Alternative treatments for cancer work better than medical remedies.
- If air gets to a cancer during surgery, it will grow faster.
- Cancer can be caused by dirty blood.
- Doctors and health professionals are the ones I would trust most to decide how to decide how to treat cancer.
- Antibiotics weaken the immune system which can lead to cancer.
- Someone can give you cancer by putting a root on you.

	<u>SA</u>	<u>AS</u>	<u>Not Sure</u>	<u>DS</u>	<u>SD</u>
People get cancer when they are tired and their resistance is down.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors can treat the symptoms of cancer but not cure the disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visualizing your body attacking cancer cells can help to cure the disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If a person worries about their cancer a lot, it will get worse.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People have spiritual needs and these should be part of the healing process.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If you keep thinking you have cancer, you will probably get it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Herbal remedies are more effective than medicines against cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors experiment with people by cutting on their cancers.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
People with thin blood are more likely to get cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nothing works to cure cancer so that it never comes back.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Positive feelings can help cure cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doctors and nurses don't know everything that there is to know about treating cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
No matter what I do, if I am going to get cancer, I will get it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If air gets in the place where the doctor cuts, then the cancer will kill you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

INFORMATION ABOUT BREAST CANCER. *I want to ask you these last few questions about any information you may have heard or seen about breast cancer within the past year. Please tell me yes or no for each of the following.*

	<u>Yes</u>	<u>No</u>	<u>Not Sure</u>
54. Within the past year, have you:			
Seen a television program on breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Read about breast cancer in a magazine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Been to a church program on breast cancer or mammography?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seen any local television commercials about breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heard a radio program or announcement about breast cancer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Been to a program at a club or civic group on breast cancer or mammography?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Read about breast cancer or mammography in the local newspaper?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Been to a program on breast cancer or mammography at work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

FAMILY INCOME

71. Please look at this card. {INTER: Hand R. Card #7.} Tell me the number that comes closest to your total family income last year. I mean the total for all the people who lived in your home last year, before taxes. Be sure to count all types of money, from wages and salaries of all family members, Social Security, retirement or unemployment benefits, help from relatives and so on. Let me remind you that this information, like all your answers, will be kept completely private.

- under \$5,000
- between \$5,000 and 7,999
- between \$8,000 and 11,999
- between \$12,000 and 15,999
- between \$16,000 and 24,999
- between \$25,000 and 49,999
- over \$50,000
- don't know

72. How many people did this income support last year? # of people supported

--	--

73. About how much do you, yourself, acutally get each month, after taxes and deductions are taken out? Please tell me the number on this card that comes closest to that amount. {INTER: Hand R. Card #8}

- up to \$50 \$801 to \$1,000
- \$51 to \$100 \$1,001 to \$2,000
- \$101 to \$200 \$2,001 to \$3,000
- \$201 to \$300 over \$3,000
- \$301 to \$500 don't know
- \$501 to \$800

