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13. ABSTRACT (Maximum 200 words) 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. A comprehensive pre-intervention survey has been completed involving almost 1200 women in 2 rural counties in eastern North Carolina. The results of this survey confirm our previous work that there is a high prevalence of certain beliefs which we have previously shown to be associated with advanced stage breast cancer. These beliefs are significantly more prevalent among African American women. The next phase of the project involves educational interventions to attempt to change some of these beliefs. A documentary video, public service announcements, brochures, and other educational materials have been developed and the intervention has just been initiated. A kick-off symposium timed to coincide with breast cancer awareness month is being held on October 6, 1998.				
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FOREWORD

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Donald R. Linn 9/28/98
PI - Signature Date

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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.

Six attitudes or beliefs about cancer have been previously identified which are widely held in North Carolina and which correlate strongly with late stage presentation of breast cancer. These beliefs are: 1) an over-reliance on God to cure cancer without medical intervention, 2) reluctance for a woman to discuss a potential cancer with her husband or male partner because he would not be supportive, 3) a general fatalism that active medical intervention would not make a difference, 4) a specific belief that cutting into a cancer or exposing it to air will make it spread faster, 5) lack of knowledge that a breast lump can be serious even if it does not hurt, and 6) belief in alternative treatments and lack of confidence in surgery as a specific therapeutic modality for breast problems.

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.

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

Body:

The progress report is organized by tasks from the statement of work.

Task 1: Hire project manager and health educator, assemble advisory board.
Complete

Task 2: Pre-intervention survey

Interviewer Recruitment and Training

During February of 1998, we held three, one-day training sessions for the 34 women (19 white and 15 African American) selected to work as interviewers on the survey research phase of the project. These women are all adult residents of the two counties in the study and were chosen because they had either performed successfully as census workers in phase one of the project or because they were recommended to us by agency coordinators in the two counties. The training session included an introduction to the goals and purpose of the overall project and of the survey instrument itself. This was followed by a discussion of the roles and responsibilities of the interviewer. In the next section of the session, project personnel discussed interview procedures and role-played techniques for handling respondents' objections to participation in the study. Interviewers were instructed in the process of obtaining informed consent from participants and practiced administering the consent form. After reviewing the survey, item by item, interviewers practiced administering the interview to one another while being observed and critiqued by the project staff.

A second aspect of the training involved extensive practice with completing the teleform survey form correctly. Interviewers had to practice hand-writing demographic information and the answers to open-ended questions in block letters and also had to practice "bubbling in" answers correctly so that they could be read by the scanner.

A third aspect of the training involved practice in the art of giving appropriate neutral feedback to respondents during the survey. Interviewers were also taught techniques for probing neutrally for detailed answers to certain questions. The session ended with instructions in how to edit surveys for completeness.

Finally, the sessions concluded with logistical information. Interviewers were given packets containing the census sheets for potential respondents, they were instructed in the number of times to make contacts, how to report information on respondent refusals, and how to file completed interviews. Interviewers were also given a package of incentive items to give respondents at the end of the interview as a thank you for the time involved. These included refrigerator magnets, potholders, and pens and tablets with the name of the Leo W. Jenkins Cancer Center on them. (A copy of the training manual and interviewer information packet are attached in the appendix).

After the training was completed, project staff observed each interviewer actually conduct an interview to make sure it proceeded smoothly. As completed interviews were returned to the office, trained graduate students checked each interview for completeness and made call-backs to the first ten respondents interviewed by each woman. The call-

backs were to verify that the interviewer had indeed been to the woman's home, had done the interview face to face and not by telephone, and that the interview had proceeded smoothly. Thereafter, call backs were made to fill in any missing information on particular surveys and every tenth interview received was routinely called for ongoing verification.

Data Collection

The census phase of the project began during the previous year and continued into the project year being covered in this report. During the census, trained adult women were sent into census track blocks to find households. For each household, they were to question a resident household member and complete a form about the number of women over age 19 residing in the home; record their names and ages and ethnic categories; determine if these women had ever had a diagnosis of breast cancer; and then explain the project to them and ascertain their potential willingness to participate in a longer interview. These forms were returned to the main office and the data were entered into a computer. Women who had received a diagnosis of breast cancer were discarded from the potential sample pool as were women who were unwilling to participate in the future.

During the previous year, we modified the final sample size for the in-depth surveys from a total of 500 women in Pitt and 500 in Wilson counties to 600 women in each county. We determined that 500 would not be a sufficient number for subgroup comparisons of three age and two race categories. In increasing the desired total sample size, we then had to increase the total number of women contacted in the census to provide a large enough sample pool from which to draw adequate numbers of respondents of each age and race subgroup. We projected initially that we would find approximately 30 per cent more women in the census than we wanted to interview so that we would have an adequate sample pool. About mid-way through the survey process, however, we had to select additional census track blocks and do more census work to identify additional women in the older age groups because of higher than anticipated rates of refusal for those groups. Thus the completed census included the names of 1700 adult women in the two counties who indicated a willingness to be surveyed. This number is slightly more than 40% of the total projected final sample.

This report is based upon surveys completed with 1046 women (541 in Pitt County and 505 in Wilson county). This number meets the goal of 500 women from each county outlined in the original grant proposal but is short of the revised goals from the first year of the project. We are presently completing the processing of interviews with the remaining 154 women needed to complete our revised sample. These should be finished by the end of September prior to the beginning of the intervention phase that begins on October 6, 1998.

The completion of the survey phase has taken longer than we planned, in part because of a higher than anticipated rate of refusal for the surveys and in part because of difficulties in locating sufficient numbers of potential respondents over age 65, particularly in Pitt County. This latter difficulty meant that we had to conduct additional census work while the survey itself was in process. The former problem meant that we had to pull new

lists of respondents continuously in order to find enough willing respondents to meet our goals.

The following tables present the breakdown of respondent refusals by county. Within each county, the number of women refusing for each age and racial group are listed.

<u>Pitt County</u>	<u>African American</u>	<u>White</u>
19-39	49	58
40-64	22	32
65 and over	14	40
Total:	85	130

<u>Wilson County</u>		
19-39	40	48
40-64	35	40
65 and over	16	40
Total:	91	128

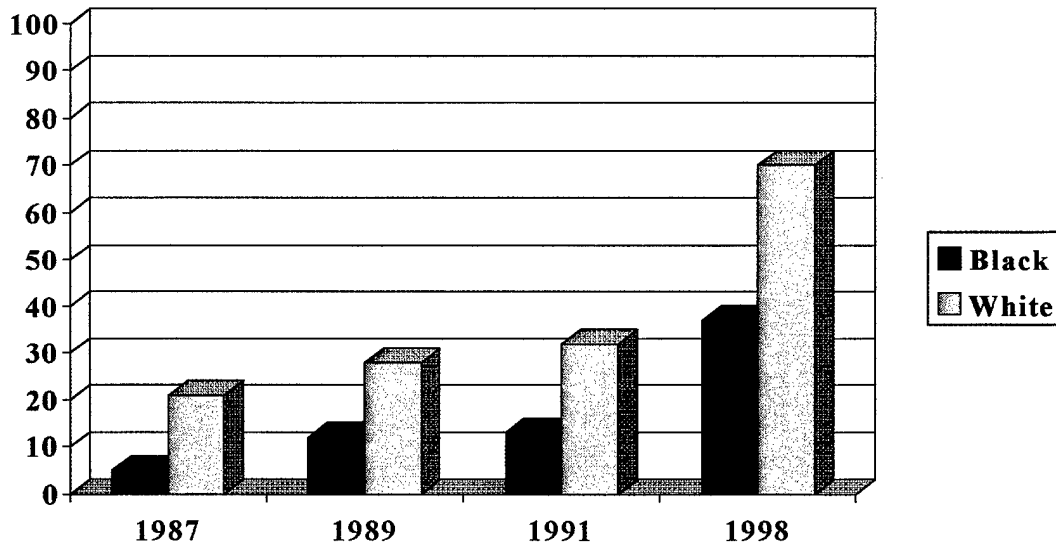
The total number of refusals for both counties is 434. The total number of women we attempted to contact and complete a survey with, therefore, was 1480. The refusal rate is the percentage of refusals out of the total number of women contacted and it is 29%. The interview completion rate to date, then, is 71%. This completion rate may seem relatively low. However, it is important to note that our category of refusals includes those women we were unable to locate because they had moved or had their telephones disconnected as well as women who had died since the time of the census or who were too ill or impaired mentally to complete the interview. Other reasons for respondent refusals included women who simply never kept established appointments with the interviewer and women who stated that they were either too busy to participate or that they were no longer interested.

Results:

The data from the pre-intervention survey is still being analyzed. However some preliminary results are presented here. Tables 1, 2, 3 give a general description of the study population. As might be expected, African American women were less educated and had less family income. Tables 4 and 5 show the percentage of women over 40 years of age who have ever had a mammogram or had a mammogram within the last year. African American women were significantly less likely to have had a mammogram. However Figure 1 shows that the overall percentage of women who have had mammograms in both races has risen dramatically since our previous surveys back in 1987 to 1991. This illustrates a remarkable change over the past decade. However since African American women are still presenting with more advanced stage cancer, it further

emphasizes our hypothesis that we will need to address barriers other than just lack of mammography.

Mammogram in the Last Year Women >50 Pitt County



The pre-intervention survey confirmed our previous results and clearly illustrated that many of the cultural beliefs and psychosocial factors which we have found to be associated with advanced stage cancer are very prevalent in the community, and more common among African American women than white women. Tables 6 to 8 illustrate that African American women are less likely to turn to their husbands or male partners for support if they develop breast cancer. Tables 9 to 11 illustrate that there is a remarkably high percentage of women who believe that air can cause a cancer to spread. We believe this is a major factor which inhibits women from seeking a biopsy for a breast lump.

Tables 12 and 13 demonstrate a lack of confidence in surgery to treat breast cancer. It is quite astounding that over 50% of African American women believe that doctors experiment with people by cutting on their cancers. Table 14 also indicates a reliance on herbal remedies rather than traditional medicines.

Finally Tables 15 through 23 clearly show a tendency to rely on fundamentalist religious beliefs or general fatalistic attitudes rather than traditional treatments for breast cancer.

Many more analyses are being performed on this data set. However it is clear that it will be a valuable resource for understanding cultural beliefs in our area and should allow us to assess the effectiveness of our educational interventions.

Tasks 3 and 4:

Development of Intervention Program

In order to plan effectively for the intervention program, a community advisory board of 30 individuals was established. The board is composed of almost equal numbers of African American and white community members. Some represent the medical professions, others are breast cancer survivors, church ministers, civic group leaders, and community activists. The board met to review plans for the intervention program and on August 18, 1998 met to assist in planning for the kickoff reception for the year-long educational intervention and to critique the recently filmed public service announcements. Advisory board members made many useful suggestions and assigned priority scores to the announcements they found most effective.

The data presented in Table 24 indicate that women in the target county are most likely to get their information on breast cancer from television. This confirmed the results of our previous study which was one of the major reasons why we decided to produce a video for use at club presentations and on television and to emphasize public service announcements on television and secondarily on radio.

The project team completed an educational video with breast cancer patients from eastern North Carolina during the previous reporting period. We were fortunate during this past year to enlist the African American actress, Anna Maria Horsford, to film a brief introduction to the video for us. The final version of the video was edited to include her introduction and copies were made for distribution during the educational campaign in Pitt County.

The project team also developed concepts for and wrote ten different public service announcements for television. Each of these was written in 10, 20 and 30 second versions for use in different broadcast formats. These public service announcements address the six themes our project emphasizes as barriers to early detection and treatment. The data from the baseline survey confirmed the importance of the six themes we had previously identified as barriers to early detection although some of the specific findings caused us to change the content of certain messages. For example, we had planned initially to address women's over-reliance on God as a barrier to early detection by formulating a message that would emphasize the compatibility of religion and medicine—the idea that God works through doctors to treat breast cancer. The data in Table 18 clearly show, however, that a majority of women already believe this. Yet many of these women still avoid treatment because they are waiting for God to heal their disease. In thinking about this issue, we also noted that data presented in Tables 15 through 23 show a tendency of about 30% of the women surveyed to be extremely fatalistic about the possibility of treating cancer and to rely on fundamentalist religious attitudes rather than use doctors. We decided that we needed to use religion more proactively in our public service announcements to promote early detection and treatment. Thus, we changed the language and focus of the announcements accordingly. For example, the announcement below, read

by the actress Anna Maria Horsford, illustrates this revised theme and has tested very positively in prescreenings with the advisory board.

God's Work

Hello, I'm Anna Maria Horsford.
I believe in the power of prayer...
Of the importance of faith in the healing process.
But I also know that God works through doctors...to cure cancer.
If you find a lump or knot in your breast...don't wait.
See your doctor right away.
God's healing is waiting for you.

The data presented in Tables 6-8 demonstrate that African American women are less likely to turn to the men in their lives for support if they develop breast cancer. This fear that a man might leave a woman with cancer is one that we had originally planned to address. But we modified our public service announcements to do two things. One is that we feature both African American male and female actresses delivering the messages and we stress the theme that women should not be afraid to tell those close to them about a problem. We are also in the process of filming two more public service announcements that portray a scene in which a woman and a man discuss her cancer and he demonstrates support. Because the data in tables 15 through 23 indicate that fatalistic attitudes are extremely pronounced in the target population, we developed announcements that use influential and persuasive actors to state directly that women must see a doctor about breast cancer because if they wait around, the cancer will grow anyway. We developed a slogan for all our public service announcements that "Cancer in your body is something that you can't live with."

The baseline data also confirm our earlier findings that local beliefs about air getting to a cancer and about cutting on a cancer causing it to spread are major barriers to timely treatment. We address these directly in our public service announcements using influential actresses to tell women these beliefs are wrong and by having a younger male talk about his grandmother's belief in air and how it caused her to die from breast cancer because she refused surgery. Finally we address women's lack of knowledge by pointing out that a lump can be serious even if it does not hurt, and that address their lack of confidence in surgery by using influential actors to promote the effectiveness of surgery. We were fortunate to obtain the services of six African American actors to make these public service announcements for us. They were Elaina Reed, Kenny Blank, Dan Martin, Roz Ryan, Clifton Davis, and Anna Maria Horsford. We are presently in the process of filming additional public service announcements with white actors. (A video tape of the public service announcements is included in the appendix).

Our media campaign also includes radio announcements that we have developed along with print advertisements and news stories to be featured in the Greenville

newspapers. In preparation for the kickoff event in October of 1998, we placed advertisements in the local newspaper and put posters in churches, grocery stores, beauty salons, laundromats, and other public locations. In addition, printed invitations were sent to a wide spectrum of community people and breast cancer survivors. A full news story on the project plus a feature story on the making of the video will appear in the Greenville newspaper, *The Daily Reflector*, a week prior to the kickoff.

We had originally planned to develop brochures as part of our intervention. The data in Table 24 indicate that a vast majority of the women surveyed have seen brochures on breast cancer. This confirmed our idea that brochures would be an effective tool. However, rather than use general messages, we planned to target these brochures to some of the six specific barriers operational in our community and to pitch them to a lower literacy level so that they would be accessible to a broad spectrum of women. Copies of some of these brochures are found in the appendix. The first of these describes the East Carolina Breast Cancer Awareness Program. The other two target the beliefs that air and cutting on a cancer will cause it to spread and women's specific fears of surgery. These brochures were developed using the GAP readability scale to make sure they target a reading level of between 6-8th grade. In this way they will be accessible to our target population.

The project team also developed the plans for the Kickoff Reception for the East Carolina Breast Cancer Awareness Program to be held on October 6, 1998. A Tuesday evening was chosen in order to avoid conflict with the schedules of many churches. The reception will be held at a local hotel and will have catered refreshments. The mayor of Greenville, the main town in Pitt County, will give a welcome and then Dr. Lannin, the project PI, will present the goals and aims for the year-long intervention program. The video, *To Live On*, will be shown for the first time and then Sylvia Dunnavant, author of *Celebrating Life: African American Women Speak Out about Breast Cancer*, will speak. The evening will end with a wrap-up by the hospital chaplain. The reception is open to the public and all who attend will be asked to register and list information on groups to which they belong so that we can contact them later about conducting an educational program for them. Tables displaying educational information on breast cancer will be set up by the local chapter of the American Cancer Society, the Partners for Breast Cancer Education Project, and our own project. We anticipate a crowd of 250-300 persons. We have advertised the reception widely in the community through the newspapers, radio, television, and we have sent invitations directly to many community leaders. In addition, the local news and television stations will cover and report the event (Copies of the newspaper advertisements, poster, and invitation are included in the appendix).

The first phase of the educational intervention itself is the presentation of a program on breast cancer using our video and the teaching objectives derived from our previous research. Letters were sent in the summer of 1998 to all civic groups, churches, and major worksites in Pitt County (about 350 organizations). The letter informed them of our program and speaker's bureau and our willingness to conduct an hour-long program for them during the year. The data in Table 24 confirm that this should be an effective new route for education as most of the women surveyed had never attended an education program on breast cancer at either a civic group, church, or work site. Groups were asked to call the office to schedule these programs. Advisory board members as well as those

attending the kickoff were also asked to approach organizations, particularly their churches, about having these programs. A speaker's bureau has been formed to present these programs. The members include the project staff, nurses and physicians from the community, trained lay health advisors from the Partners in Breast Cancer Education program in Pitt County, breast cancer survivors and retired teachers. A manual of standard information on breast cancer risk, screening recommendations, and treatment options has been prepared for each member of the bureau (see appendix for a copy) and a training session has been developed which will instruct speakers in how to facilitate discussion of the major myths and barriers to early detection found in our previous research. These educational sessions will begin in October immediately after the kickoff reception. A standard reporting form for each presentation has been developed so that speakers can record the location of the program and the number of people in attendance. Attendees will also be asked to complete a short evaluation form about the content of the presentation.

With the assistance of one of our advisory board members, Dr. David White of the Department of Health Education at East Carolina University, we are in the process of developing a modified version of our educational program suitable for presentation in high school health courses for 10th graders. The program will not only emphasize information on breast cancer and the importance of early detection, but also the program will focus on enlisting high school students to encourage their older female relatives to see a doctor for a regular breast exam and mammogram.

The final component of our intervention phase is an outreach project for OB-GYN offices. We will ask all the OB-GYN physicians in Pitt County to implement a program that will provide their patients with information on breast cancer that can be taken home and given to their older female relatives. Data from the baseline survey indicates that this is an important new approach since 41% of the African American and 39% of the white women surveyed in the target county said that their physicians had asked them if their mothers or grandmothers had breast cancer but only 11.2% of African American and 4.2% of white women had ever been asked by their physicians to share information about breast cancer with their relatives. The OB-GYN outreach program is still being developed with assistance from faculty in the OB-GYN department at the ECU School of Medicine. We anticipate beginning this program in the next two months.

Table 1. Distribution by age.

	COUNTY			
	pitt		wilson	
	RACE		RACE	
	b	w	b	w
	age category	age category	age category	age category
	%	%	%	%
under 40	32.4%	30.6%	43.2%	27.7%
41 - 65	43.8%	43.6%	41.8%	36.7%
over 65	23.8%	25.7%	15.0%	35.5%

Table 2. Distribution by education.

	COUNTY			
	pitt		wilson	
	RACE		RACE	
	b	w	b	w
	education	education	education	education
	%	%	%	%
< HS	43.1%	12.1%	42.3%	19.1%
HS	29.2%	20.8%	29.1%	22.3%
>HS	27.8%	67.1%	28.6%	58.6%

Table 3. Distribution by family income.

	COUNTY			
	pitt		wilson	
	RACE		RACE	
	b	w	b	w
	Family Income	Family Income	Family Income	Family Income
	%	%	%	%
<16 k	65.8%	19.3%	57.4%	19.5%
16 to 50 k	29.5%	43.6%	35.1%	50.0%
> 50 k	4.8%	37.1%	7.4%	30.5%

Table 4. Have you ever had a mammogram?
(women > 40)

	COUNTY			
	pitt		wilson	
	RACE		RACE	
	b	w	b	w
	Ever had mammogram	Ever had mammogram	Ever had mammogram	Ever had mammogram
	%	%	%	%
Yes	71.1%	92.3%	81.5%	88.5%
No	28.9%	7.7%	18.5%	11.5%

Table 5. Have you had a mammogram in the last year?
(women > 40)

	COUNTY			
	pitt		wilson	
	RACE		RACE	
	b	w	b	w
	Had mammogram in last year	Had mammogram in last year	Had mammogram in last year	Had mammogram in last year
	%	%	%	%
Yes	38.0%	64.3%	56.0%	64.3%
No	62.0%	35.7%	44.0%	35.7%

Table 6. A man would probably leave a woman if he knew that she had to have her breast removed.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	man would probably leave a woman if breast removed	man would probably leave a woman if breast removed	man would probably leave a woman if breast removed	man would probably leave a woman if breast removed
	%	%	%	%
Agree	5.7%	1.6%	1.4%	1.6%
Disagree	19.0%	8.8%	21.8%	5.9%
Not sure	45.2%	84.4%	72.7%	84.4%
	30.0%	5.2%	4.1%	8.2%

a. black vs white p < .0005

Table 7. A woman is more likely to get support from her female friends or relatives when she is seriously ill than from the man in her life.

	COUNTY			
	pitt		wilson	
	RACE		RACE ^a	
	b	w	b	w
	better support from female friends than man	better support from female friends than man	better support from female friends than man	better support from female friends than man
	%	%	%	%
Agree	5.2%	1.6%	1.4%	1.6%
Disagree	61.4%	34.5%	48.6%	26.2%
Not sure	24.3%	61.2%	47.3%	66.0%
	9.0%	2.6%	2.7%	6.3%

a. black vs white p < .0005

Table 8. A man would probably not stay with a woman if he knew that she had breast cancer.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	man would not stay with a woman if had breast cancer	man would not stay with a woman if had breast cancer	man would not stay with a woman if had breast cancer	man would not stay with a woman if had breast cancer
	%	%	%	%
Agree	5.2%	1.6%	1.4%	1.6%
Disagree	11.0%	3.6%	13.2%	2.7%
Not sure	56.2%	90.2%	78.6%	85.2%
	27.6%	4.6%	6.8%	10.5%

a. black vs white p < .0005

Table 9. If air gets to a cancer during surgery, the cancer will grow faster.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	Air causes growth	Air causes growth	Air causes growth	Air causes growth
	%	%	%	%
	Agree	70.3%	35.8%	64.7%
Disagree	29.7%	64.2%	35.3%	53.8%

a. black vs white $p < .0005$

Table 10. Air getting to a cancer during surgery will not make it spread.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	Air will not make it spread	Air will not make it spread	Air will not make it spread	Air will not make it spread
	%	%	%	%
	Agree	19.9%	58.7%	23.7%
Disagree	80.1%	41.3%	76.3%	54.8%

a. black vs white $p < .0005$

Table 11. If air gets in the place where the doctor cuts, then the cancer will kill you.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	If air gets in, will kill you	If air gets in, will kill you	If air gets in, will kill you	If air gets in, will kill you
	%	%	%	%
	Agree	57.0%	11.7%	37.5%
Disagree	43.0%	88.3%	62.5%	81.2%

a. black vs white $p < .0005$

Table 12. It is better to die whole than to let a doctor cut on your body.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	die whole	die whole	die whole	die whole
	%	%	%	%
Agree	9.2%	3.7%	13.6%	3.6%
Disagree	90.8%	96.3%	86.4%	96.4%

a. black vs white $p < .0005$

Table 13. Doctors experiment with people by cutting on their cancers.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	Doctors experimen t by cutting	Doctors experimen t by cutting	Doctors experimen t by cutting	Doctors experimen t by cutting
	%	%	%	%
Agree	57.9%	29.8%	53.3%	35.9%
Disagree	42.1%	70.2%	46.7%	64.1%

a. black vs white $p < .0005$

Table 14. Herbal remedies are more effective than medicines against cancer.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	Herbal remedies better than medicines	Herbal remedies better than medicines	Herbal remedies better than medicines	Herbal remedies better than medicines
	%	%	%	%
Agree	21.5%	7.4%	18.8%	4.3%
Disagree	78.5%	92.6%	81.3%	95.7%

a. black vs white $p < .0005$

Table 15. The strength of your own faith in God would determine if your cancer was cured.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	strength in your faith would determine cure	strength in your faith would determine cure	strength in your faith would determine cure	strength in your faith would determine cure
	%	%	%	%
Agree	4.8%	3.6%	5.9%	1.6%
Undecided	65.2%	26.1%	64.1%	16.8%
disagree	14.8%	3.3%	6.8%	8.6%
	15.2%	67.1%	23.2%	73.0%

a. black vs white p < .0005

Table 16. You would want your church members to come to the hospital to pray with you.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	want church members to come to hospital	want church members to come to hospital	want church members to come to hospital	want church members to come to hospital
	%	%	%	%
Agree	4.8%	3.6%	5.9%	1.2%
Undecided	77.6%	62.9%	82.7%	70.3%
disagree	8.6%	4.9%	3.6%	3.9%
	9.0%	28.7%	7.7%	24.6%

a. black vs white p < .0005

Table 17. There would be a special ceremony for you in your church to cure your cancer.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	special ceremony for you in church	special ceremony for you in church	special ceremony for you in church	special ceremony for you in church
	%	%	%	%
Agree	4.8%	3.6%	5.9%	1.6%
Undecided	44.8%	25.7%	40.5%	16.0%
disagree	13.8%	9.1%	3.6%	9.0%
	36.7%	61.6%	50.0%	73.4%

a. black vs white p < .0005

Table 18. God would work through the doctors and nurses to cure your cancer.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	God would work through doctors	God would work through doctors	God would work through doctors	God would work through doctors
	%	%	%	%
Agree	4.8%	3.6%	5.9%	1.2%
Undecided	92.9%	85.7%	91.8%	90.2%
disagree	1.0%	1.6%	1.4%	3.1%
	1.4%	9.1%	.9%	5.5%

a. black vs white p < .0005

Table 19. You would trust more in God to cure your cancer than medical treatment.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	trust more in God than medical treatment	trust more in God than medical treatment	trust more in God than medical treatment	trust more in God than medical treatment
	%	%	%	%
Agree	4.8%	3.6%	5.9%	1.2%
Undecided	66.2%	33.6%	66.8%	20.3%
disagree	12.9%	13.4%	7.3%	7.8%
	16.2%	49.5%	20.0%	70.7%

a. black vs white p < .0005

Table 20. You would refuse medical treatment and trust only in God to cure your cancer.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	refuse medical treatment and trust only in God	refuse medical treatment and trust only in God	refuse medical treatment and trust only in God	refuse medical treatment and trust only in God
	%	%	%	%
Agree	4.8%	3.6%	5.9%	1.2%
Undecided	3.8%	.3%	6.8%	.8%
disagree	2.4%	.7%	3.2%	.4%
	89.0%	95.4%	84.1%	97.7%

a. black vs white p < .0005

Table 21. Only a religious miracle could cure your cancer, not medical treatment.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	only religious miracle could cure, not medical treatment	only religious miracle could cure, not medical treatment	only religious miracle could cure, not medical treatment	only religious miracle could cure, not medical treatment
	%	%	%	%
Agree	5.2%	3.6%	5.9%	1.2%
Undecided	19.5%	5.5%	26.8%	3.5%
disagree	14.8%	2.9%	7.7%	3.1%
	60.5%	87.9%	59.5%	92.2%

a. black vs white p < .0005

Table 22. Your cancer would be because you had sinned against God.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	cancer because you had sinned against God'	cancer because you had sinned against God'	cancer because you had sinned against God'	cancer because you had sinned against God'
	%	%	%	%
Agree	4.8%	3.6%	5.9%	1.6%
Undecided	7.1%		3.6%	.8%
disagree	2.4%		1.8%	.8%
	85.7%	96.4%	88.6%	96.9%

a. black vs white p < .0005

Table 23. It would be your responsibility to pray every day that God would cure your cancer.

	COUNTY			
	pitt		wilson	
	RACE ^a		RACE	
	b	w	b	w
	your responsibi lity to pray every day	your responsibi lity to pray every day	your responsibi lity to pray every day	your responsibi lity to pray every day
	%	%	%	%
Agree	4.8%	3.6%	5.9%	1.2%
Undecided	86.2%	58.0%	80.9%	60.5%
disagree	2.4%	1.6%	4.1%	4.7%
	6.7%	36.8%	9.1%	33.6%

a. black vs white p < .0005

Table 24. Within the past year, have you:

Col %

		COUNTY			
		pitt		wilson	
		race		race	
		b	w	b	w
Seen a tv program or commercial about breast cancer?	yes	72.9%	82.1%	76.4%	84.4%
	no	18.6%	15.0%	22.3%	11.3%
	not sure	3.3%	1.3%	.0%	2.3%
	missing	5.2%	1.6%	1.4%	2.0%
		100.0%	100.0%	100.0%	100.0%
Read about breast cancer in a magazine?	yes	46.7%	74.9%	58.6%	78.9%
	no	46.7%	22.5%	40.0%	18.0%
	not sure	1.0%	1.0%	.0%	1.6%
	missing	5.7%	1.6%	1.4%	1.6%
		100.0%	100.0%	100.0%	100.0%
Heard a radio program or commercial about breast cancer?	yes	41.4%	40.1%	54.1%	44.1%
	no	51.4%	56.7%	44.1%	52.7%
	not sure	1.4%	1.6%	.5%	1.6%
	missing	5.7%	1.6%	1.4%	1.6%
		100.0%	100.0%	100.0%	100.0%
Read about breast cancer in the newspaper?	yes	33.3%	62.2%	43.6%	66.4%
	no	61.0%	34.5%	54.5%	30.5%
	not sure	.5%	1.6%	.5%	1.6%
	missing	5.2%	1.6%	1.4%	1.6%
		100.0%	100.0%	100.0%	100.0%
Been to a church program on breast cancer or mammography?	yes	11.9%	4.6%	7.3%	1.2%
	no	82.9%	93.5%	90.9%	97.3%
	not sure	.0%	.3%	.5%	.0%
	missing	5.2%	1.6%	1.4%	1.6%
		100.0%	100.0%	100.0%	100.0%
Been to a program at a club or civic group on breast cancer or mammography?	yes	3.3%	8.1%	5.0%	7.8%
	no	90.5%	89.6%	93.2%	90.6%
	not sure	.5%	.0%	.0%	.0%
	missing	5.7%	2.3%	1.8%	1.6%
		100.0%	100.0%	100.0%	100.0%
Been to a program on breast cancer or mammography at work?	yes	8.6%	9.1%	10.0%	9.4%
	no	85.7%	88.6%	88.2%	89.1%
	missing	5.7%	2.3%	1.8%	1.6%
		100.0%	100.0%	100.0%	100.0%
Seen a pamphlet about breast cancer or mammography?	yes	69.0%	82.7%	68.2%	69.1%
	no	24.3%	15.0%	30.5%	28.9%
	not sure	.5%	.7%	.0%	.4%
	missing	6.2%	1.6%	1.4%	1.6%
		100.0%	100.0%	100.0%	100.0%
Seen a video about breast cancer or mammography?	yes	19.5%	18.2%	17.7%	12.1%
	no	74.8%	79.8%	80.9%	85.5%
	not sure	.5%	.0%	.0%	.4%
	missing	5.2%	2.0%	1.4%	2.0%
		100.0%	100.0%	100.0%	100.0%

Col %

		COUNTY			
		pitt		wilson	
		race		race	
		b	w	b	w
Participated in any local American Cancer Society activities like Relay for Life?	yes	5.7%	15.3%	7.7%	15.2%
	no	89.0%	82.7%	90.9%	82.8%
	not sure	.0%	.3%	.0%	.4%
	missing	5.2%	1.6%	1.4%	1.6%
		100.0%	100.0%	100.0%	100.0%
Picked up information about breast cancer at a health fair?	yes	35.7%	21.2%	21.8%	19.5%
	no	59.0%	76.9%	76.8%	78.5%
	not sure	.0%	.3%	.0%	.4%
	missing	5.2%	1.6%	1.4%	1.6%
		100.0%	100.0%	100.0%	100.0%

Conclusions:

Baseline data confirm many of our previous findings concerning the targeted beliefs which are associated with advanced breast cancer. There were some surprising new findings, however, that we will need to accommodate in the intervention program. One of these is the belief that surgeons experiment by cutting on patients. Women in our sample are extremely skeptical about the effectiveness and purposes of surgical treatment. Another is stronger than expected adherence to the belief that God works through doctors to treat cancer.

Through the use of the video, public service announcements, and brochures which provide culturally sensitive educational messages, we hope to educate women about the importance of screening and the symptoms of the disease, thus leading to diagnosis at an earlier, more treatable stage. Our ultimate goal is to reduce breast cancer mortality. This approach and the findings will not be limited to eastern North Carolina but can be utilized in any area where similar psychosocial beliefs are prevalent.

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Influence of Socioeconomic and Cultural Factors on Racial Differences in Late-Stage Presentation of Breast Cancer

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Context.—Breast cancer mortality is higher among African American women than among white women in the United States, but the reasons for the racial difference are not known.

Objective.—To evaluate the influence of socioeconomic and cultural factors on the racial difference in breast cancer stage at diagnosis.

Design.—Case-control study of patients diagnosed as having breast cancer at the University Medical Center of Eastern Carolina from 1985 through 1992.

Setting.—The major health care facility for 2 rural counties in eastern North Carolina.

Subjects.—Five hundred forty of 743 patients with newly diagnosed breast cancer and 414 control women from the community matched by age, race, and area of residence.

Main Outcome Measures.—Breast cancer stage at diagnosis.

Results.—Of the 540 patients, 94 (17.4%) presented with TNM stage III or IV disease. The following demographic and socioeconomic factors were significant predictors of advanced stage: being African American (odds ratio [OR], 3.0; 95% confidence interval [CI], 1.9-4.7); having low income (OR, 3.7; 95% CI, 2.1-6.5); never having been married (OR, 2.9; 95% CI, 1.4-5.9); having no private health insurance (OR, 2.5; 95% CI, 1.6-4.0); delaying seeing a physician because of money (OR, 1.6; 95% CI, 1.1-2.5); or lacking transportation (OR, 2.0; 95% CI, 1.2-3.6). Univariate analysis also revealed a large number of cultural beliefs to be significant predictors. Examples include the following beliefs: air causes a cancer to spread (OR, 2.8; 95% CI, 1.8-4.3); the devil can cause a person to get cancer (OR, 2.1; 95% CI, 1.2-3.5); women who have breast surgery are no longer attractive to men (OR, 1.9; 95% CI, 1.1-3.5); and chiropractic is an effective treatment for breast cancer (OR, 2.4; 95% CI, 1.4-4.4). When the demographic and socioeconomic variables were included in a multivariate logistic regression model, the OR for late stage among African Americans decreased to 1.8 (95% CI, 1.1-3.2) compared with 3.0 (95% CI, 1.9-4.7) for race alone. However, when the belief measures were included with the demographic and socioeconomic variables, the OR for late stage among African Americans decreased further to 1.2 (95% CI, 0.6-2.5).

Conclusions.—Socioeconomic factors alone were not sufficient to explain the dramatic effect of race on breast cancer stage; however, socioeconomic variables in conjunction with cultural beliefs and attitudes could largely account for the observed effect.

ALTHOUGH breast cancer incidence is somewhat lower among African American women than among white women in the United States, breast cancer mortality is consistently higher among African Americans.¹⁻⁵ A large part of the explanation for this is that African Americans present with more advanced-stage disease.⁶⁻¹² The reasons for this racial difference in stage, however, are not clear. Socioeconomic factors have been shown to strongly influence the stage of disease presentation¹³⁻¹⁶ and may partially account for the difference. African Americans have less access to medical care and are less likely to undergo breast cancer screening.^{17,18} Most studies, however, show that socioeconomic variables alone do not account for all of the observed effect.^{11,19-23} Even when universal access to medical care is ensured, there are still racial disparities in breast cancer diagnosis and outcome.^{24,25}

Cultural factors such as beliefs, attitudes, and knowledge about cancer are also known to vary dramatically by race,²⁶⁻³² and the importance of these cultural factors is increasingly recognized. No study to date, however, has shown a direct relationship between these cultural factors and breast cancer stage or mortality, nor have the interactions among socioeconomic factors, cultural factors, and race been explored.

In 1988 a comprehensive, long-term study to evaluate factors that influence breast cancer diagnosis, treatment, and outcome was started at the Leo W. Jenkins Cancer Center of East Carolina University, Greenville, NC. Emphasis was placed on psychosocial factors as well as medical factors. This report presents study results showing how race, socioeconomic factors, and cultural factors interact to influence breast cancer stage at diagnosis.

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Table 1.—Demographics of Study and Control Populations*

Characteristics	Study Population (n = 540)	ECU Patients Not in Study (n = 202)	Patients From State Tumor Registry† (n = 2004)	Control Group Without Cancer (n = 414)
Race				
White	70	74	75	70
African American	30	26	25	30
Age, y				
>65	34	48	48	36
50-65	34	33	30	37
<50	32	19	22	27
Income, \$ per capita in family				
>10 000	44	NA	NA	50
5000-10 000	29	NA	NA	25
<5000	27	NA	NA	25
Education				
>High school	39	NA	NA	40
High school	27	NA	NA	27
<High school	34	NA	NA	33
Married				
Ever	92	91	NA	94
Never	8	9	NA	6
Tumor stage				
Local	60	54	60	...
Regional	33	32	32	...
Distant	7	14	8	...

*All numbers are percentages. ECU indicates East Carolina University; NA, not available. Ellipses indicate data not applicable.

†Data from the North Carolina State Tumor Registry for the 20 surrounding counties for 1988-1992 excluding the study patients.

METHODS

Patient Population

The University Medical Center of Eastern Carolina (consisting of East Carolina University School of Medicine, Pitt County Memorial Hospital, and the local private-practice community) is the only inpatient or surgical health care facility in Pitt County or Greene County and is the regional tertiary care referral center for the 29 surrounding counties in eastern North Carolina. Numerous marketing surveys have shown that over 95% of all Pitt County and Greene County residents and a significant percentage of the population of the surrounding counties who require inpatient care or surgery receive this at the facility. The area is predominately rural, and the largest town has a population of fewer than 60 000. The population of the entire referral area is about 1.5 million, of whom one third are African American. About 25% of the population lives below the federal poverty level, compared with 14.4% nationally.³³

Starting in 1988 all patients diagnosed as having breast cancer between January 1, 1985, and December 31, 1992, at the University Medical Center of Eastern Carolina were evaluated for interview. Of the 743 white or African American patients diagnosed (1 person each of Asian and Hispanic ethnicity was excluded), 37 (5%) of the total died before interviews could be completed, and another 35 (5%) either moved out of eastern North Carolina prior

to being interviewed or were determined to be either physically or mentally incapable of being interviewed. Of the 671 patients still resident in eastern North Carolina and well enough to be interviewed, 53 (8%) refused to participate in the project, and 1 physician at the medical center refused to allow his 78 patients (12%) to participate. Therefore, interviews were completed with 540 of the 671 eligible patients for a response rate of 80%. Interviews were conducted as soon as possible after diagnosis; 58% were completed within 3 months, 70% within 1 year, and 90% within 3 years of the date of diagnosis.

About half of the interviewed patients were residents of Pitt County or Greene County, and the other half were from 20 surrounding counties. Table 1 shows demographics for the patients interviewed, patients treated at the medical center but not interviewed, and patients in the North Carolina State Tumor Registry for the 20 surrounding counties who were not interviewed. The study participants were slightly younger than patients who did not participate, but Table 1 suggests they were otherwise representative of all breast cancer patients in eastern North Carolina.

Control Population

The study also included a control group of community-dwelling women without breast cancer from eastern North Carolina matched to each breast cancer patient by race, age, and residence type (ie, rural nonfarm, rural farm, small town, large

town). These control women were interviewed in their homes with the same instrument administered to the patients.

A multistage, stratified, random procedure developed and used previously by members of the research team³⁴ was used to identify a pool of adult women older than 25 years living in Pitt County or 4 adjacent counties in eastern North Carolina. These counties each demonstrated demographic and residential variability similar to that found in the 20 eastern North Carolina counties from which the patient population was derived. Sampling began with the random selection of 15 census enumeration districts (equivalent to track blocks) from within the 5 counties with a minimum of 2 enumeration districts from each county. With maps to define enumeration district boundaries, a door-to-door canvass identified 1350 households containing eligible adult women. Verbal consent to participate in the study was obtained during the initial contact, and women who had breast cancer were eliminated from the potential respondent pool. About 90% of those contacted initially agreed to participate in the project. Households were then stratified by residential type (households on rural farms, small towns, and so forth) and by race and age categories of the women residents. As each breast cancer patient was entered into the study, a control subject was chosen randomly from all women in the respondent pool who matched the patient by age, race, and residence categories.

A total of 414 matched controls were interviewed over the 5-year study period. There were 135 more patients interviewed than controls. This difference occurred because control group sampling and interviews lagged behind patient interviews. As the end of the funding cycle approached, a preliminary analysis of the data indicated that a sufficient number of controls existed to conduct statistical comparisons with the patient population, and a decision was made to end control group recruitment. The data in Table 1 verify that there are no significant differences in demographic and socioeconomic characteristics between the patient and control groups.

Interview and Data Collection

Each patient and matched control was interviewed in person by a sex- and race-matched interviewer. Thirty older adult women residents of the study counties, who had never had breast cancer, were recruited as interviewers. Interviewers were paid to attend 2 intensive day-long training sessions that taught the procedures for obtaining informed consent, the mechanics for administering and recording responses on the structured interview guide, and ways to minimize bias

in the interview encounter and to probe neutrally for more feedback. The project team observed 10% of the interviews conducted by each interviewer, and call-backs were made to each of the first 10 respondents visited by an interviewer to make sure she had indeed been in the home and that the interview had proceeded smoothly. The project team edited every interview for completeness and checked for any inconsistencies in response patterns signaling the need to modify the interviewer's techniques.

Interviewers were matched to patients and controls by race, but within racial categories, each interviewer received assignments randomly. The interviewers knew only that the patients had been diagnosed as having breast cancer, and they were given no additional information. Since none of the interviewers received any specific training in breast cancer, it is doubtful that they were aware at all of stage differences or attentive to any clues in physical appearance that might have signaled such differences. They knew only that we wanted to learn more about the reasons why women did or did not seek medical care for breast cancer.

The structured interview was developed based on preliminary in-depth interviews by a cultural anthropologist with a random sample of patients diagnosed previously at the institution. The instrument was subsequently pretested by project staff on both clinic and control populations and revised prior to the beginning of the study. The final structured interview included 173 questions in a variety of closed-ended answer formats on the topics of demographics, health history, support systems, socioeconomic status, and beliefs and attitudes regarding breast cancer, cancer treatment, and health care in general. Many of the questions related health care to cultural factors such as folk beliefs, religious beliefs, and attitudes regarding family and relationships with men.

Questions were read to the respondent by the interviewer since many of the respondents had low literacy levels. The structured interview took a mean time of 50 minutes to complete. At the end of the structured component, each patient was asked 10 open-ended questions about her particular illness experience, and these were analyzed separately from the answers to the structured interview.

Tumor Stage

Data regarding tumor stage was collected from each patient's medical record. Tumors were staged using the American Joint Committee on Cancer's *Manual for Staging of Cancer*. When the project first began, the second edition of the manual (1983) was used and tumors

Table 2.—Reason Patient Presented for Medical Care*

Stage and Race	Breast Lump or Symptom	Screening Physician Breast Examination	Screening Mammogram	Symptom of Metastases
Early stage				
White (n = 327)	54†	12	34‡	...
African American (n = 118)	70†	15	15‡	...
Late stage				
White (n = 45)	85†	4	2	9
African American (n = 48)	84†	6	2	8

*All numbers are percentages. Ellipses indicate data not applicable.

†Combined early stage vs combined late stage, $P < .001$.

‡White vs African American, $P < .001$.

that were TNM stage III or IV were considered "advanced stage," whereas all others were considered "early stage." In subsequent editions of the manual, T3, N0 tumors (ie, tumors >5 cm) are now considered stage IIB instead of stage III. For consistency, we defined any tumor larger than 5 cm as "advanced stage," including all stage III and IV cancers and some stage IIB tumors.

Analysis

Data were analyzed for statistical significance using the logistic regression procedures of SPSS software version 7.5. Tumor stage was the dependent variable dichotomized as either early or late. Various demographic, socioeconomic, or cultural factors were the independent variables. Per capita income was calculated by dividing household income by the number of people supported by that income and categorized as more than \$10 000, between \$5000 and \$10 000, or less than \$5000. Age and education were also split into 3 categories: younger than 50 years, aged 50 to 65 years, or older than 65 years; and less than high school education, high school graduate, or more than high school education. The cultural variables were all dichotomized into true and false or agree and disagree answers.

Univariate analyses were performed to describe the relationship between each of the independent variables and tumor stage. Odds ratios (ORs) and 95% confidence intervals (CIs) were calculated for each comparison. The prevalence of each of the cultural beliefs among race, income, age, education, and tumor status (ie, either patient or control) subgroups was also analyzed using univariate techniques. In these analyses, holding a particular belief was considered the dependent variable, and each of the demographic characteristics was the independent variable. The effect of race was studied both alone and adjusted for income, age, and education.

Multivariate logistic regression models were constructed to evaluate the influence of race, socioeconomic factors, and cultural factors on tumor stage. The potential interaction of race with the socioeconomic and cultural factors was assessed with a hierarchical backward

elimination approach described by Kleinbaum.³⁵ Determination of whether the socioeconomic and cultural factors were potential confounders of race involved examination of the ORs for different models containing the socioeconomic and cultural factors.

RESULTS

Method of Presentation of Breast Cancer Patients

Of the 540 patients interviewed, 94 (17.4%) presented with advanced-stage disease. The method of presentation of the breast cancer patients is shown in Table 2. Whereas a significant percentage of early-stage cancers were found on screening mammography or screening clinical breast examination, almost all patients with late-stage cancers presented with breast symptoms or symptoms of distant metastases. In many cases the tumor replaced a large portion of the breast. About 25% of the late-stage patients had frank ulceration, which led to bleeding or tissue infection.

Effect of Demographic and Socioeconomic Factors on Tumor Stage

The association of a variety of demographic and socioeconomic factors with advanced disease stage is shown in Table 3. Being African American, having a per capita income of \$10 000 or less, and lacking private health insurance all had a major impact on disease stage. In addition, as might be expected, patients who reported that they had put off seeing a physician because of money or transportation problems were also significantly more likely to present with late-stage disease. Never having been married was also significantly associated with stage, perhaps because these women lacked both the financial and social support provided by a spouse. Age did not have a significant association with stage at presentation and, surprisingly, the relationship between education and stage was only marginally significant.

Effect of Psychosocial and Cultural Factors on Tumor Stage

Table 4 shows a variety of cultural and psychosocial factors that all had a signifi-

Table 3.—Association of Late-Stage Disease With Demographic and Socioeconomic Variables

Variables	Early Stage, No. (%)	Late Stage, No. (%)	OR (95% CI)*
Race			
White	328 (88)	45 (12)	1.0 (. . .)
African American	118 (71)	49 (29)	3.0 (1.9-4.7)
Age, y			
>65	157 (85)	28 (15)	1.0 (. . .)
50-65	152 (83)	32 (17)	1.2 (0.7-2.0)
<50	137 (80)	34 (20)	1.4 (0.8-2.4)
Income, \$ per capita in family†			
>10 000	211 (91)	22 (9)	1.0 (. . .)
5000-10 000	124 (82)	28 (18)	2.2 (1.2-4.0)
<5000	101 (72)	39 (28)	3.7 (2.1-6.5)
Education			
>High school	180 (86)	30 (14)	1.0 (. . .)
High school	121 (83)	25 (17)	1.2 (0.7-2.2)
<High school	145 (79)	39 (21)	1.6 (0.9-2.7)
Married			
Ever	423 (84)	81 (16)	1.0 (. . .)
Never	23 (64)	13 (36)	2.9 (1.4-5.9)
Private health insurance			
Some	344 (86)	54 (14)	1.0 (. . .)
None	101 (72)	40 (28)	2.5 (1.6-4.0)
Ever put off seeing doctor because of money?			
No	326 (85)	59 (15)	1.0 (. . .)
Yes	119 (77)	35 (23)	1.6 (1.1-2.5)
Difficulty finding transportation to doctor?			
No	394 (84)	74 (16)	1.0 (. . .)
Yes	52 (72)	20 (28)	2.0 (1.2-3.6)

*OR indicates odds ratio, ie, (No. of late African Americans/No. of early African Americans)/(No. of late whites/No. of early whites); CI, confidence interval.
†Income data missing for 15 persons.

cant influence on tumor stage when tested independently. These cultural factors seem to fall into the following categories: health care utilization, folk beliefs, fundamentalist religious beliefs, relationships with men, perceived risk or fatalism, belief in various treatments for breast cancer, and breast cancer knowledge. Not having a regular physician or seeing the physician once a year or less was highly associated with advanced disease presentation. Women who held any of the culturally derived folk beliefs, fundamentalist religious beliefs, or beliefs about relationships with men or fatalism were all significantly more likely to present with late-stage disease. In contrast, women who scored correctly on 2 breast cancer knowledge items were significantly less likely to present with late-stage disease. Belief that herbs, medicines, or chiropractic are effective treatments for breast cancer also correlated positively with late-stage disease, whereas belief in the effectiveness of surgery was associated with early presentation.

Prevalence of Psychosocial and Cultural Beliefs Within Demographic Subpopulations

There were strong, consistent patterns in the prevalence of the psychosocial and cultural beliefs among demographic subpopulations. Most of the folk beliefs, fundamentalist religious beliefs,

and beliefs about fatalism or relationships with men were significantly more common among African Americans and among those with lower income or less education. In contrast, knowledge about breast cancer was significantly more common in whites, upper-income persons, and better educated women. Although the psychosocial and cultural variables were associated with income, age, and education, the majority of them correlated most closely with race. Table 5 shows that most of the variables were significantly associated with race even when adjusted for age, income, and education. Interestingly, however, health care utilization, as measured by having a regular physician and number of yearly visits, did not seem to differ by race.

Comparison of Patient and Control Groups

Table 5 also shows the prevalence of these cultural beliefs in women from the control population compared with breast cancer patients. Many of the beliefs showed very similar distributions in both groups. Not surprisingly, breast cancer patients were less likely than controls to believe that "people who take good care of themselves usually don't get cancer" (ie, OR for patients compared with controls, <1), and more likely than controls to believe that "health professionals control their health" (ie, OR for

patients compared with controls, >1). In addition, the patients had much stronger belief in surgery as an effective treatment for breast cancer. Most importantly, however, several of the folk beliefs and fundamentalist religious beliefs that were associated with late-stage cancer were actually more prevalent in the control group than in the patient group. Clearly these beliefs did not result from experiences related to having breast cancer or interacting with the health care team but rather were preexistent in the general population.

Multivariate Modeling of Race and Socioeconomic and Cultural Factors on Tumor Stage

To assess the confounding of socioeconomic and cultural factors on race and to evaluate the relative importance of these variables in predicting breast cancer stage, various multivariate models were constructed. Before analyzing the models, the assessment of race as a possible effect modifier was performed by analyzing the interaction of race with each socioeconomic and cultural factor using a backward elimination procedure.³⁵ There were no statistically significant interactions. Next, the effect of race on tumor stage was assessed both alone and when the socioeconomic or cultural variables were added as a group to the model as potential confounders. Table 6 shows that the OR for advanced disease among African Americans compared with whites decreased from 3.0 to 1.8 when either the socioeconomic variables or the cultural variables were added to the model. When both the socioeconomic and cultural variables were added to the model, the OR diminished further to 1.2. Thus, it appears that both the socioeconomic and cultural variables are strong confounders of race and together can largely account for the effect of race on late-stage disease presentation.

COMMENT

The most important reason for the lower survival rate from breast cancer among African American women compared with white American women¹⁻⁵ is that African American women present with more advanced-stage disease.⁶⁻¹² The reasons for this disparity in stage, however, are not completely understood. While several investigators have emphasized the relative importance of socioeconomic status in influencing access to physician care and screening services,¹³⁻¹⁶ others have found that socioeconomic effects alone cannot account for all of the difference,^{11,19-23} and yet others have emphasized the possible role of biological differences in tumor characteristics.^{7,26,37} Race is used by many in-

Table 4.—Association of Late-Stage Disease With Cultural and Psychosocial Variables

Variables	Answer	Early Stage, No. (%)	Late Stage, No. (%)	OR (95% CI)*
Health care utilization				
Do you have a regular doctor?	Yes	413 (85)	74 (15)	1.0 (. . .)
	No	32 (61)	20 (39)	3.5 (1.9-6.4)
How many times have you seen your doctor in the past year?	>1	407 (85)	70 (15)	1.0 (. . .)
	≤1	39 (62)	24 (38)	3.6 (2.0-6.3)
Folk beliefs				
Air causes a cancer to grow faster	False	312 (88)	43 (12)	1.0 (. . .)
	True	134 (72)	51 (28)	2.8 (1.8-4.3)
Surgery causes a cancer to grow faster	False	209 (86)	35 (14)	1.0 (. . .)
	True	237 (80)	59 (20)	1.5 (1.0-2.3)
People with high blood are more likely to get cancer†	False	402 (85)	74 (15)	1.0 (. . .)
	True	44 (69)	20 (31)	2.5 (1.4-4.4)
People with thin blood are more likely to get cancer†	False	398 (84)	74 (16)	1.0 (. . .)
	True	48 (71)	20 (29)	2.2 (1.3-3.9)
Someone can give you a cancer by putting a root or spell on you†	False	437 (83)	87 (17)	1.0 (. . .)
	True	9 (56)	7 (44)	3.9 (1.4-10.8)
If a person worries about their cancer, it will get worse	False	205 (86)	34 (14)	1.0 (. . .)
	True	241 (80)	60 (20)	1.5 (1.0-2.4)
Fundamentalist religious beliefs				
If a person prays about cancer, God will heal it without medical treatments	False	393 (84)	75 (16)	1.0 (. . .)
	True	53 (74)	19 (26)	1.9 (1.1-3.3)
The devil can cause a person to get cancer	False	377 (85)	68 (15)	1.0 (. . .)
	True	69 (73)	26 (27)	2.1 (1.2-3.5)
Relationships with men				
Women who have surgery for breast cancer are no longer attractive to men	False	400 (84)	77 (16)	1.0 (. . .)
	True	46 (73)	17 (27)	1.9 (1.1-3.5)
Men would not want to know if the women in their life had breast cancer	False	375 (84)	70 (16)	1.0 (. . .)
	True	71 (75)	24 (25)	1.8 (1.1-3.1)
Men are more attracted to women without problems	False	152 (88)	20 (12)	1.0 (. . .)
	True	294 (80)	74 (20)	1.9 (1.1-3.2)
Perceived risk or fatalism				
If a lump in breast is not bothersome, there is no need to consult a doctor	False	438 (83)	87 (17)	1.0 (. . .)
	True	8 (53)	4 (47)	4.4 (1.6-12.4)
People who take good care of themselves usually don't get cancer	False	418 (84)	79 (16)	1.0 (. . .)
	True	28 (65)	15 (35)	2.8 (1.5-5.5)
If a woman finds a breast lump, the worst that can happen would be surgery	False	273 (86)	43 (14)	1.0 (. . .)
	True	173 (77)	51 (23)	1.9 (1.2-2.9)
When I get sick, I am to blame	False	365 (85)	67 (15)	1.0 (. . .)
	True	81 (75)	27 (25)	1.8 (1.1-3.0)
If it's meant to be, I will stay healthy	False	142 (87)	21 (13)	1.0 (. . .)
	True	304 (81)	73 (19)	1.6 (0.9-2.7)
Health professionals control my health	False	267 (86)	44 (14)	1.0 (. . .)
	True	179 (78)	50 (22)	1.7 (1.1-2.7)
Belief in treatment for breast cancer				
Herbs	False	385 (84)	74 (16)	1.0 (. . .)
	True	61 (75)	20 (25)	1.7 (1.0-3.0)
Medicines	False	131 (87)	20 (13)	1.0 (. . .)
	True	315 (81)	74 (19)	1.5 (0.9-2.6)
Surgery	False	16 (59)	11 (41)	1.0 (. . .)
	True	430 (84)	83 (16)	0.3 (0.1-0.6)
Chiropractic	False	404 (84)	75 (16)	1.0 (. . .)
	True	42 (69)	19 (31)	2.4 (1.4-4.4)
Breast cancer knowledge				
Women without children have a greater chance of getting breast cancer	False	303 (80)	75 (20)	1.0 (. . .)
	True	143 (88)	19 (12)	0.5 (0.3-0.9)
If a woman has breast cancer, her daughter is likely to get it too	False	201 (79)	54 (21)	1.0 (. . .)
	True	245 (86)	40 (14)	0.6 (0.4-0.9)

*OR indicates odds ratio, ie, (No. of late true/No. of early true)/(No. of late false/No. of early false); CI, confidence interval.

†"High blood," "thin blood," and a "root" are traditional African American folk terms.

investigators to refer mainly to overt phenotypic differences, usually of skin color, and is rarely, if ever, operationalized in terms of specific gene frequencies. The

American Anthropological Association argues in its Statement on Race³⁸ that modern humans (*Homo sapiens*) are a fairly recent and homogeneous species,

and genetic data indicate that there is as much genetic variability between 2 people from the same "racial" group as there is between 2 people from any 2 different "racial" groups. Thus, there are few biological differences between these large population groups that are of explanatory relevance.³⁹

To the extent that the individuals labeled as belonging to a particular race or ethnic group share certain beliefs, attitudes, and behaviors (culture), they may come to engage in similar health practices and may develop similar illness profiles. Recently, many studies have shown that there is a large difference among races in breast cancer knowledge, beliefs, and attitudes.^{26-32,40-42} This has been shown to influence cancer screening and prevention behaviors,^{28,30,43-47} but until now has not been shown to directly influence stage at diagnosis. Our results demonstrate clearly that psychosocial and cultural variables directly influence stage and, in combination with socioeconomic variables, are sufficient to explain the difference in stage between African Americans and whites.

An important question is how the cultural beliefs that we have identified led to diagnosis of breast cancer at a more advanced stage. In our study, 30% of the cancers in whites and 11% in African Americans were discovered by routine screening mammography. Obviously cancers discovered by screening at an early stage do not become advanced, and therefore, part of the explanation may be that the cultural beliefs were associated with differential use of screening mammography. However, O'Malley et al,⁴⁸ in a study involving women in the same community at the same time, found that women's knowledge and beliefs had very little influence on use of screening mammography, and the most important factor was whether it was recommended by a physician. Furthermore, in our study the majority of early-stage cancers as well as late-stage cancers were found by the patient. Therefore, we believe that the most important effect of the cultural beliefs is that they lead to delayed presentation once a woman has developed a palpable breast abnormality. This would also be consistent with the finding of Jones et al⁴⁹ that mammography alone does not explain all of the racial differences in stage of diagnosis.

Our previous analysis⁵⁰ of the open-ended portion of the interviews with African American women with late-stage disease allows some understanding of the reasoning process involved and demonstrates that cultural conceptions of breast lumps and cancer directly influence women's recognition and evaluation of breast symptoms. These women

Table 5.—Difference in Prevalence of Cultural Beliefs by Race in Patient and Control Groups*

Cultural Beliefs	Percentage Who Agree				OR (95% CI), Patient Control†	OR (95% CI), African American/ White‡	Adjusted OR (95% CI), African American/ White§
	Patients		Controls				
	White (n = 373)	African American (n = 167)	White (n = 288)	African American (n = 126)			
Health care utilization							
No regular doctor	8	14	5	11	1.4 (0.9-2.3)	2.0 (1.2-3.1)	1.3 (0.7-2.2)
<2 Visits to doctor	11	13	30	21	0.4 (0.3-0.5)	0.8 (0.6-1.2)	0.9 (0.6-1.4)
Folk beliefs							
Air causes cancer growth	25	55	35	84	0.5 (0.4-0.7)	4.9 (3.6-6.6)	3.3 (2.3-4.6)
Surgery causes cancer growth	52	61	58	87	0.6 (0.5-0.8)	2.1 (1.6-2.9)	1.4 (1.0-2.0)
High blood causes cancer	8	21	8	20	1.0 (0.7-1.5)	3.0 (2.0-4.4)	1.7 (1.1-2.7)
Thin blood causes cancer	8	23	10	25	0.8 (0.6-1.2)	3.3 (2.2-4.7)	2.1 (1.3-3.3)
Root or spell causes cancer	1	7	1	15	0.5 (0.3-1.0)	9.3 (4.2-21)	5.7 (2.2-14)
Worry makes cancer worse	52	65	55	75	0.8 (0.6-1.1)	2.0 (1.5-2.6)	1.6 (1.1-2.2)
Fundamentalist religious beliefs							
God will cure without medical treatment	6	30	6	47	0.7 (0.5-1.0)	9.5 (6.4-14)	4.5 (2.9-7.0)
Devil causes cancer	11	31	10	33	1.0 (0.7-1.4)	3.8 (2.7-5.4)	2.1 (1.4-3.2)
Relationships with men							
Surgery makes women not attractive	9	16	7	18	1.2 (0.8-1.8)	2.4 (1.6-3.6)	1.4 (0.8-2.2)
Men would not want to know about cancer	13	28	10	43	0.9 (0.6-1.2)	4.2 (3.0-5.8)	3.1 (2.0-4.6)
Men attracted to women without problems	69	66	70	73	0.8 (0.6-1.1)	1.0 (0.7-1.4)	0.8 (0.6-1.1)
Perceived risk and fatalism							
No doctor if lump not bothersome	0	8	2	11	0.6 (0.3-1.1)	9.0 (4.0-20)	6.0 (2.3-15)
No cancer if take good care of themselves	5	16	11	29	0.5 (0.3-0.7)	3.3 (2.2-4.9)	2.2 (1.4-3.5)
If lump, worst thing would be surgery	36	55	34	48	1.1 (0.9-1.5)	2.0 (1.5-2.6)	1.6 (1.1-2.2)
When sick, I am to blame	15	31	20	26	0.9 (0.6-1.2)	1.9 (1.4-2.6)	1.5 (1.1-2.3)
If it's meant to be, I will stay healthy	65	81	56	81	1.4 (1.0-1.8)	2.8 (2.0-3.9)	2.0 (1.3-2.9)
Health professionals control my health	39	50	26	33	1.9 (1.4-2.4)	1.5 (1.1-2.0)	1.1 (0.8-1.6)
Belief in treatments							
Herbs	9	28	9	22	1.2 (0.8-1.7)	3.5 (2.4-5.1)	2.6 (1.7-4.1)
Medicines	67	84	68	78	1.0 (0.8-1.4)	2.1 (1.5-2.9)	2.0 (1.3-2.9)
Surgery	96	93	90	70	3.8 (2.4-6.0)	0.3 (0.2-0.5)	0.5 (0.3-0.9)
Chiropractic	6	24	3	14	1.9 (1.2-3.1)	5.1 (3.2-8.1)	3.0 (1.8-5.2)
Breast cancer knowledge							
Increased risk if nulliparous	33	23	34	18	1.1 (0.8-1.4)	0.5 (0.4-0.7)	0.8 (0.6-1.2)
Increased risk for daughter	60	38	49	40	1.3 (1.0-1.7)	0.5 (0.4-0.7)	0.6 (0.5-0.8)

*OR indicates odds ratio; CI, confidence interval.

†Odds ratio is (No. of cancer patients agree/No. of cancer patients disagree)/(No. of controls agree/No. of controls disagree).

‡Odds ratio is (No. of African Americans agree/No. of African Americans disagree)/(No. of whites agree/No. of whites disagree).

§Adjusted for income, age, and education.

||"High blood," "thin blood," and a "root" are traditional African American folk terms.

Table 6.—Relative Odds for Late-Stage Disease*

Variables in Model	OR (95% CI)†
Race alone	3.0 (1.9-4.7)
Race, socioeconomic factors‡	1.8 (1.1-3.2)
Race, cultural factors§	1.8 (1.0-3.2)
Race, socioeconomic, and cultural factors	1.2 (0.6-2.5)

*Africans Americans compared with whites, multivariate modeling.

†OR indicates odds ratio, ie, (No. of late African Americans/No. of early African Americans)/(No. of late whites/No. of early whites); CI, confidence interval.

‡Socioeconomic factors are all factors from Table 3.

§Cultural factors are all factors from Table 4.

interpreted their symptoms with reference to a traditional or "folk" model of the blood. In terms of this model, breast lumps are not necessarily bad. They are a normal part of a woman's system as evinced by the fact that if left alone, they tend to come and go. Consequently, patients reported that "lumps that aren't bothering you are best left alone." However, lumps often change, and once a lump begins to "take on a life of its own," it may become bothersome. This transi-

tion was reported by patients to happen for several reasons—either a blow or bruise to the breast triggers the growth, or an ever-increasing number of impurities in the blood begins to "move up" or "grow out," or a lump stays in 1 place too long and begins to "take root."

Recognizing that a lump is growing and becoming bothersome, however, does not necessarily imply that a woman will seek medical treatment for it. The majority of patients with late-stage presentation believed that "letting air get to a cancer" or "cutting on a cancer" was to be avoided because it would cause the cancer to spread. Instead, many advocated the use of alternative treatments including herbal remedies, over-the-counter medications, chiropractic regimens, and, perhaps most importantly, prayer and a reliance on God to heal the disorder. Finally, a significant number of the African American women presenting with late-stage disease were reluctant to seek medical treatment for cancer because of their fears about how

the disease would impact on their relationships with the men in their lives. These women were afraid that their husbands or male partners would leave them if a cancer diagnosis became known, both because they would no longer be physically attractive but also because they might become burdens to men financially and emotionally.

A very important question is whether the results presented in this article can be generalized to a larger population. It seems likely that the attitudes and beliefs identified are fairly widespread throughout the rural southeastern United States. Whether they will be found to apply to inner-city African Americans in the northern or western areas of the United States, however, will require further study. If the cultural beliefs are found to be regionally specific, at least the principle that cultural beliefs and socioeconomic factors act together to explain the racial effect on tumor stage at diagnosis may be broadly applicable.

The findings reported here have important implications for physicians. Physicians must be aware of the cultural and psychosocial biases of their patients and address them in culturally sensitive ways. If physicians understand their patients' fears and misconceptions about breast cancer, they will be more effective in promoting behavior that may allow early detection and treatment. For example, physicians can explain that air and surgery do not make breast cancer spread, but instead early removal offers the best chance for cure. To counteract the fatalistic notion that the breast cancer is part of God's plan, it is helpful to promote the concept that God works through physicians to cure breast cancer. Finally, physicians must be aware of a patient's concern about the influence a diagnosis may have on her husband or partner and deal with this in a sensitive manner.

These findings also have positive implications for cancer education efforts and public health interventions. If the racial difference in breast cancer stage at diagnosis were purely socioeconomic, this would be very discouraging as economic issues are difficult to change. However, by recognizing that at least part of the problem is cultural, it may be possible to modify key beliefs in a way that would lead to earlier breast cancer diagnosis and still be consistent with the underlying cultural attitudes of the target population. Promotion of increased breast examination and mammography in the absence of research on the compatibility of these practices with predominant cultural beliefs will fail to have the desired impact. This may explain why recent community interventions in Detroit, Mich,⁵¹ and North Carolina¹⁷ increased breast cancer screening significantly more among white women than among African American women. However, interventions that address the specific cultural beliefs and psychosocial attitudes identified in this research may be effective at decreasing the excess stage III and IV cancer among African Americans. Although these cancers account for only 15% to 30% of the total, they have a high mortality and contribute significantly to the difference in survival rates by race.

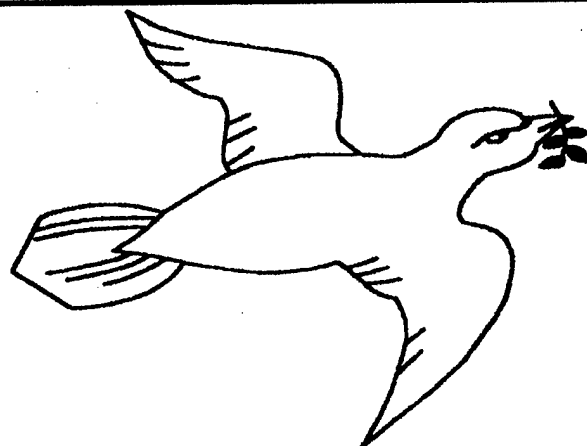
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**EAST CAROLINA
BREAST CANCER AWARENESS
PROGRAM
(EC-BCAP)**

**INTERVIEWER
TRAINING MANUAL**

February 27, 1998
PCMH Teaching Annex, Rm. 247
10:00a.m.-4:00p.m.

*East Carolina University
Leo W. Jenkins Cancer Center*

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PROJECT PERSONNEL

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Jonathan Newton, Graduate Student Assistant
MBA Program, ECU School of Business
(919) 816-5418

PROJECT GOAL

The major reason that some women in our region have poor survival from breast cancer is that they present with advanced stage disease. 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 goal of this project is to develop methods to encourage earlier detection of breast cancer in an area. A community-wide intervention is scheduled to begin in early 1998 in an attempt to promote breast screening and alter those cultural beliefs and practices that may cause some women to delay getting treatment. The intervention will utilize educational messages through television, radio, and newspaper; educational programs conducted through local churches, businesses and schools; and a unique program where older women are reached through their younger relatives who are seeing Ob-Gyn physicians.

PURPOSE OF SURVEYS

The educational intervention will be performed in the experimental county, Pitt County, and the effects compared to a control county, Wilson County, where no intervention is performed. Community-wide surveys will be done in each county before and after the intervention to determine how well the intervention effected the area. The two counties were chosen because they have similar populations and a similar range of medical facilities. This four year study will consist of data collection and assessment in years one and four and the intervention in years two and three.

ROLES AND RESPONSIBILITIES OF AN INTERVIEWER

Be familiar with the purpose and importance of the project so you can answer questions about the project.

Remember that all of the women you will be interviewing have spoken with an interviewer before. We call the women we speak to, **Respondents**. These Respondents want to be heard and are usually happy that they are given an opportunity to talk. They are often willing to share their thoughts if they are convinced that their responses will be of some help to others. If you, as an interviewer, believe that the information obtained from the survey is important, your tone and manner will convey that importance to the Respondents.

Know how to confront problems and less-than-ideal circumstances “in the field.”

Most problems will be minor and can be handled as they occur. For example, should an unexpected emergency (i.e. car problems, etc.) result in the delay or cancellation of a scheduled interview, be responsible enough to call and inform the Respondent.

More serious problems (i.e. your inability to fulfill your role as an interviewer) should be brought to the attention of the project manager, Frances Swanson. Her phone number is (919) 816-5418.

Keep what is learned from or about Respondents confidential.

Everyone working on this project must maintain confidentiality. All information obtained during the interview that concerns Respondents or their families is privileged information. You should never talk about a Respondent's answers or use her name. Information should not be shared with your family, friends, or other Respondents. The information

may only be shared with the project personnel listed on page 3. We expect all interviewers to follow this rule.

Be attentive to your appearance.

Your appearance is important to a successful interview. Try to dress in the middle range between very formal and very informal. We want you to be comfortable, but we also want Respondents to feel comfortable around you. Dressing too formally (i.e. business suits, etc.) may intimidate some Respondents or make them feel inadequate. Dressing too informally (i.e. torn or stained clothing, old or faded sweat pants, T-shirts, etc.) may offend others or cause them to doubt your professionalism.

Also be advised that certain personal habits such as smoking and gum chewing may turn Respondents off. Do not engage in such activities once you arrive at a Respondent's home.

Put the Respondent at ease so that she will feel free to answer personal questions.

The best way to do this is to be and feel relaxed. Show a compassionate attitude and an interest in the Respondent's answers.

Although it is your responsibility to listen attentively, you should always maintain a certain degree of personal distance. For example, if the Respondent shifts the conversation to topics not relevant to the interview, direct her back to the survey.

Personal safety should always be considered.

Some suggestions for maintaining your personal safety include:

- Try to schedule interviews during daylight hours. If you must schedule one at night, ask the Respondent to leave a light on for you.
- Do not wear a lot of expensive jewelry and consider locking any valuables in your trunk if you do not want to carry them with you.
- Do not go into any situation where you feel uncomfortable. As an example, if a threatening dog is present, or if other people in the home seem threatening, leave and telephone the Respondent, as soon as possible, to reschedule if possible.
- Do not be afraid to terminate an interview if you feel threatened. Do not jeopardize your safety under any circumstances.

INTERVIEW PROCEDURES

How were women selected?

The women were identified in a door-to-door census conducted in Pitt and Wilson counties. A random sample of women were selected in each age group from the two county area. Census forms with the names, addresses, and telephone numbers of the women selected will be given to each interviewer to contact.

How to contact the women on your census forms?

Once you have received the names of the women you are to interview, you need to contact them to set up appointments for the interviews. If there is no phone number listed on the form, you must reach them by direct contact by visiting the woman's home. This visit can be to set up an appointment or you can try to conduct the interview at that time.

Planning rules:

- 1- Interview only the women whose names are on the forms you are given. Never interview someone whose name is not on the census forms. Maintaining the random selection of the sample is vital to the scientific accuracy of this study.
- 2- Plan your trips so that you can interview more than one person in the area, if at all possible. Schedule plenty of time between appointments.
- 3- Be punctual and avoid changing appointment times. If a woman is not home or breaks an appointment, contact her as soon as possible to reschedule. If you have to change an appointment, apologize to the Respondent and reschedule the appointment at her earliest convenience.
- 4- All interviews must be conducted in person. It is not acceptable to interview someone over the telephone. If A Respondent asks you to do the interview over the phone, tell her that you need to do it in person because you must show her certain parts of the interview.

MATERIALS TO BRING TO EACH INTERVIEW:

- Interview booklet (bring more than one).
- Census forms of those women being interviewed that day.
- Notebook with interview materials including cards, consent forms, and pens.
- Name tag to be worn on your clothing.

HOW TO RESPOND TO RESPONDENTS' REFUSALS

Respondent: "I don't have time to do this."

You: "It should only take about 1 hour to 1 1/2 hours to complete the interview. I'm very flexible and we can do it at any time that is good for you."

Respondent: "I'm really not interested."

You: "It is very important that we interview everyone whose name was picked so we have a good understanding of what women think in your area. If we don't talk to everyone, the results won't be very helpful. So if you would please reconsider, I would greatly appreciate it."

Respondent: "I don't have any health problems."

You: "We are interested in interviewing all women even if they don't feel that they have any health problems. Interviewing everyone helps us look at things that may affect good as well as bad health".

Respondent: "I don't like studies like these".

You: "We understand that many people don't like to be asked a lot of personal questions, but this study is very important to help us learn some things that can hopefully improve the health of all women in this state. That's why we are talking to many different kinds of women in your county."

Respondent: “My health is no one else’s business.”

You: “I can certainly understand if you feel this way. If you decide to speak to us, you are being generous with your time. All our interviews are confidential, and your name will not be put with answers you give. Protecting people’s privacy is one of our major concerns. You may skip any questions you want to.”

Respondent: “I don’t think I know enough to try to answer these questions.”

You: “These questions are not hard and there are no right or wrong answers. The questions ask for your opinions about certain things like your health and what you do to keep healthy. Some of the women interviewed were concerned at first but were at ease after we got started with the questions.”

CONDUCTING THE INTERVIEW

1. **Introduce yourself:** My name is _____ and I am from the EC-BCAP. (Show the letter or card with the phone number.)
2. **Remind the Respondent that she was contacted before.** (Census, letter explaining her selection as part of the study, phone call setting up the interview.)
3. **Thank her for agreeing to participate** in the project and ask her if she has any questions before you start the interview.
4. **Put the Respondent at ease.** Show genuine interest and be relaxed and friendly. Your sincerity and interest in the Respondent's feelings and family will help establish empathy.
5. **Keep your introductory remarks brief.** Try to avoid excessive conversing and do the interview as soon as possible. Be courteous and let her know you can talk after the interview is over.
6. **Try to interview the respondent alone.** Ask if there is a place the two of you can go so you will not be interrupted. Let her know the interview will go much faster if there are no interruptions.
7. **You must get the Respondent's informed consent to participate in the project before the interview begins.** These forms must be read and signed before you start the interview. Leave one copy of the informed consent with the Respondent and turn in the other one.
8. **Stress that there are no right or wrong answers and that her opinions are very valuable to doctors and to other women like herself.** Remind her that she was chosen along with the other women to let us know about their health care experiences.

QUESTIONS OFTEN ASKED

Respondent: “What is this study about?”

You: “This interview is part of a study on women’s health being conducted by East Carolina University and the Leo W. Jenkins Cancer Center in Greenville. We are doing this study to learn more about health care practices for serious illnesses of women in Pitt County”.
(Do not say that this interview is about breast cancer or getting mammograms; it could bias the questions.)

Respondent: “Is this private?”

You: “We are very concerned about confidentiality and protecting your privacy. Your name will not be mentioned to anyone and all the results are written up in a way that does not identify any individual. Your answers will never be put together with your name”.

Respondent: “What kind of questions do I have to answer?”

You: “The questions are mostly about what you think about taking care of your health. I’ll be asking you about illnesses you may have had, things you do to stay healthy, and what you do when you get sick. These are really easy questions and there are no right or wrong answers. We are very interested in your opinion and the opinions of other women like you”.

Respondent: “Why did you choose me?”

You: “In order to get our list of women to interview, we used a computer to select women “like the flip of a coin” for us to talk to. We interview only the women the computer selects so we may or may not interview any of your neighbors. It is very important to us to talk to all the women on our lists so we can get good information.

HOW TO ASK SURVEY QUESTIONS

There are two types of questions that will be used in the questionnaire: **closed-ended and open-ended.**

Closed-ended questions are questions that have response categories on the interview you fill in. Closed ended questions can end with a question mark (?) or a colon (:). Here are examples of each:

Ex. 1 Have you ever had a mammogram?
 o YES o NO o (S.C. Not sure)

Ex. 2 Do you attend church:
 o On a regular basis
 o Occasionally
 o On special events or holidays
 o never

For a closed-ended question, always read the question and all of the possible answers. After this, fill in the circle(s) of the answer(s) given by the Respondent. S.C. means silent code so do not read this answer to the Respondent.

Open-ended questions just have a line for you to write in the answers. Some of these questions will have boxes for you to fill in the answers.

Ex. 1 Why haven't you ever had a mammogram?

Write down the Respondent's exact words. Begin writing as soon as the Respondent begins speaking. It may be helpful to repeat what was said to make sure you write every word.

Things to be careful about when asking questions:

- Use a pleasant tone of voice. Show interest in what the Respondent is saying, be confident, and have a professional manner.
- Make eye contact to show you're interested. Don't do things that indicate you might be judging the Respondent, like raising your eyebrows or frowning.
- Read questions slowly, about 2 words per second.
- Read each question exactly as it is written. ADD nothing. Skip nothing.
- Emphasize underlined words with your voice to give them more meaning.
- Don't forget to read transition statements that begin a section. These statements help set the tone for the questions that follow.
- Don't read out loud our instructions to you. These instructions will be labeled {INTER} and are in **boldface print**. Remember, S.C. means Silent Code. Answers with S.C. are not intended to be read out loud.
- Read the entire question and all multiple answers to the Respondent before accepting the Respondent's answer. If the question ends with a question mark(?), you may not have to read the answers. If the question ends with a colon(:), you will need to read all of the answers to the Respondent. When a question has a card with it, point to the answers on the card as you say them.
- Don't skip questions unless the instructions say to do so. If the Respondent has already given you information that answers the question, you can comment:

"I know we've talked about this..." or "I know you just mentioned this but I need to ask every question as it is written in the questionnaire."

To get accurate information from Respondents, it is important that you ask all questions in a uniform manner. That is, ask all Respondents the same questions in the same way and in the same order.

If a Respondent doesn't understand the question, don't try to explain to her what you think the question means. Instead, use one of the following methods:

- Repeat the entire question. Use this technique if you think the Respondent didn't hear the question.
- Repeat part of the question. Use this technique when the Respondent is unsure of what you are asking.
- Repeat all possible response categories if the Respondent asks you to repeat any of them.
- Use the Vocabulary List at the end of the manual to give the definitions of some of the difficult words in the brochure. Take the Vocabulary List to each interview to ensure consistency.

Giving different explanations, synonyms, or clarifications to different Respondents means the questions are not being asked in a uniform or standard manner. This also means the questions won't be the same questions for all Respondents. When this happens, we can't be sure the answers are what the women really think or believe.

Recording Answers

The interview booklet is printed in a teleform format. All of the answers to the questions will be scanned into the computer for collection rather than manual collection. The scanner is very sensitive so, therefore, it is important that the answers be recorded correctly.

Guidelines for recording answers:

- Always use the black felt tip pens which were provided. Extra pens will be available through the main office when they are needed.
- When filling in boxes, print neatly IN ALL CAPS so that each letter fits in a square. Skip spaces between words that are not connected. Be sure to distinguish between letters and numbers that look similar.

Ex. The letter "I" should be printed with the stems so it does not look like the number "1".

- Fill in the circles completely, trying not to stray outside of it. If you mark an incorrect answer, place a X on the wrong answer then fill in the circle of the correct answer.
- Try to avoid making stray marks on the interview. Take extra paper in case you need to make personal notes or messages.

FEEDBACK

You can provide feedback to reward the Respondent for giving thoughtful answers.

- Give short feedback for short responses like:
 - “I see.....”
 - “Uh-huh”
 - “Thank you”
 - “Thanks”
- Give longer feedback when the Respondent gives longer or more complicated answers:
 - “That’s useful/helpful information”
 - “It’s useful to get your ideas on this”
 - “It’s important to get your opinion on this, thank you”
 - “I see; that’s helpful to know”
 - “It’s important to find out what women think about this”
- Pause before giving feedback. Your pause signals the Respondent that you have considered her answer carefully.
- Don’t give feedback if the Respondent goes off track or doesn’t answer the question.

Feedback should not be judgmental or show support for one answer over another. For example, don’t say, “I agree with you on that” or “That’s very good”. This could bias the women to give answers she feels you will be pleased with.

PROBING

Probes are used when a Respondent's answers are unclear. Probing helps to clarify the Respondent's answers or to focus the Respondent on the specific content of the question and answer.

Ex. You: Different women have told us that they would do things.
How likely would you be to go to the doctor if you found a lump?
Would you be:
o very likely o likely o not likely

Respondent: I would say likely or very likely.

This response is unclear because the Respondent did not choose one of the three options. The Respondent must be asked in a neutral way to clarify which option she would like to choose. Do not fill in two responses without trying, neutrally, to get the Respondent to give you one answer.

Some examples of neutral probes are:

- Pause for a while. A pause gives the Respondent time to be more thoughtful when answering.
- Repeat the question or part of the question. This involves simply repeating the response choices. Repetition is used if the Respondent does not seem to understand the question or needs more to think.
- Ask clarifying questions.
 - "What do you mean?"
 - "Would you tell me more about your thinking on that?"
 - "What do you think?" or "What do you expect?"
 - "Which would be closer to the way you feel?"
- Pauses and repetition of the question are the best neutral probes to use when appropriate.

EDITING

Editing means rechecking the interview schedule after the interview, and out of sight of the Respondent, to be sure it is complete. Editing should be done as soon as possible after you have finished the interview.

- Make sure you fill in all the items on the cover page and the back page. Be sure to include your interviewer number, date of the interview, and the Respondent's information.
- Review the interview to be sure that every question that should be answered has a response. It is a good idea to check this before leaving the Respondent's home or while you are in the car before you leave the area. If anything is missing, it is likely that you will have to contact the Respondent again to get the information.
- Make sure the answers to the open-ended questions are written legibly. Fill in any words where you may have used shorthand during the interview.
- Be sure to write your comments in the space provided on the last page.

TRAINING AGENDA

Introductions

Packet materials

Explanation of purpose of project

Signing of forms

Distribution of census maps

Map-reading exercise

Distribution of census forms

Form completion exercise

Explanation of logistics; payment forms; pick-up process, etc.

Questions/answers

Conclusion

LIST OF ECU CONTACTS FOR
THE BREAST CANCER RESEARCH PROJECT

DONALD LANNIN, M.D.	(919) 816-5418	DEPT OF SURGERY
FRANCES SWANSON, M.S.	(919) 816-5418	DEPT OF SURGERY
KIMBERLY BEST	(919) 816-5418	DEPT OF SURGERY
JIM MITCHELL, Ph.D.	(919) 816-2793	ECU CENTER ON AGING
HOLLY MATHEWS, Ph.D.	(919) 328-4839	DEPT OF ANTHROPOLOGY

****PLEASE TAKE COMPLETED FORMS IN ENVELOPE PROVIDED TO:**

***PITT COUNTY MEMORIAL HOSPITAL
ROOM 304
DR. LANNIN'S OFFICE***

****PLEASE DELIVER BY NOON EACH FRIDAY**

LIST OF ECU CONTACTS FOR THE BREAST CANCER RESEARCH PROJECT

DONALD LANNIN, M.D.	(919) 816-5418	DEPT OF SURGERY
FRANCES SWANSON, M.S.	(919) 816-5418	DEPT OF SURGERY
KIMBERLY BEST	(919) 816-5418	DEPT OF SURGERY
JIM MITCHELL, Ph.D.	(919) 816-2793	ECU CENTER ON AGING
HOLLY MATHEWS, Ph.D.	(919) 328-4839	DEPT OF ANTHROPOLOGY

****PLEASE TAKE COMPLETED FORMS IN ENVELOPE PROVIDED TO:**

***WILSON COUNTY HEALTH DEPARTMENT
1801 GLENDALE DRIVE
WILSON, NC 27893
(919) 2915470***

Census Worker

--	--

Block Group Number

O Wilson

[illegible]

--	--	--	--	--

Last Name

[illegible][illegible][illegible]

Zip Code

[illegible]

--	--

--	--	--	--	--

--	--	--	--

Date of Birth:

--	--

Had Breast Cancer?

☐ Yes☐ No

☐ Other

Telephone Number

()

				-				
--	--	--	--	---	--	--	--	--

Best time of day to be found at home?

☐ morning ☐ afternoon ☐ evening

(may check more than one)

Directions to the Home:



School of Medicine

Department of Surgery

919-816-2393 clinic appointments
919-752-4163 after 5:00 p.m.
919-816-2089 fax

BREAST CANCER RESEARCH PROJECT

Biostatistics and Computing

816-2148

M. S. Swanson, PhD

Cardiothoracic Surgery

818-4822

W. R. Chitwood, Jr., MD

J. R. Elbeery, MD

T. G. Koutlas, MD

R. M. Lust, PhD

J. E. Miller, MD

J. F. Moran, MD

J. M. Williams, MD

Colon/Rectal Surgery

816-3810

K. G. MacDonald, MD

William H. H. Chapman III, MD

P. G. Meade, MD

Endoscopy 816-4171

K. G. MacDonald, MD

William H. H. Chapman III, MD

M. B. Foil, MD

D. R. Lannin, MD

P. G. Meade, MD

Epidemiology

816-3582

J. M. Dolezal, PhD

General Surgery

816-4629

P. R. Cunningham, MD

William H. H. Chapman III, MD

M. B. Foil, MD

D. R. Lannin, MD

K. G. MacDonald, MD

P. G. Meade, MD

T. N. Patselas, MD

W. J. Pories, MD

L. Tafta, MD

R. W. Youngblood, MD

Plastic Surgery 816-5291

W. A. Wooden, MD

J. C. Benacci, MD

Surgical Curriculum

816-5262

S. S. Cox, PhD

Surgical Oncology

816-5418/4629

D. R. Lannin, MD

W. J. Pories, MD

L. Tafta, M.D.

Thoracic Surgery

816-4629

W. R. Chitwood, Jr., MD

J. R. Elbeery, MD

T. C. Koutlas, MD

J. E. Miller, MD

J. F. Moran, MD

W. J. Pories, MD

J. M. Williams, MD

R. W. Youngblood, MD

Trace Element Center

816-2963

R. H. Maier, PhD

W. J. Pories, MD

Transplantation

816-2614

C. E. Haisch, MD

P. R. Cunningham, MD

K. M. Verbanac, PhD

Trauma/Critical Care

816-4299

P. R. Cunningham, MD

M. B. Foil, MD

C. E. Haisch, MD

T. N. Patselas, MD

Vascular Surgery

816-4667

C. S. Powell, MD

W. M. Bogey, MD

D. H. Deaton, MD

This is a study conducted by physicians and scientists from the Leo Jenkins Cancer Center and East Carolina University. The project is funded by the Department of Defense. The goal of this project is to design better ways to educate women about breast cancer.

We will be asking women in Pitt and Wilson Counties questions about their beliefs, opinions, and behaviors related to breast cancer and its treatment. Using this information, we will develop educational messages for use on television and radio, in the newspaper, and at local churches, businesses, schools, and doctors offices. Our ultimate aim is to provide the knowledge necessary to encourage women to use available resources to detect breast cancer early when it is most curable.

We are here today to see if you will help us in this project by agreeing to visit with a woman in your home later to answer the questions related to breast cancer. This discussion will take place in your home, will last about an hour, and will be kept confidential.

If you have any questions about this project, you may call the project manager Frances Swanson, MS at (919) 816-5418 at the Department of Surgery, ECU School of Medicine in Greenville. Thank you for your help in this important project.

Greenville,
North Carolina
27858-4354

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School of Medicine

Department of Surgery

919-816-2393 clinic appointments
919-752-4163 after 5:00 p.m.
919-816-2089 fax

May/June, 1997

Biostatistics and Computing
816-2148
M. S. Swanson, PhD

Cardiothoracic Surgery
818-4822
W. R. Chitwood, Jr., MD
J. R. Elbeery, MD
T. G. Koutlas, MD
R. M. Lust, PhD
J. E. Miller, MD
J. F. Moran, MD
J. M. Williams, MD

Colon/Rectal Surgery
816-3810
K. G. MacDonald, MD
William H. H. Chapman III, MD
P. G. Meade, MD

Endoscopy 816-4171
K. G. MacDonald, MD
William H. H. Chapman III, MD
M. B. Foil, MD
D. R. Lannin, MD
P. G. Meade, MD

Epidemiology
816-3582
J. M. Dolezal, PhD

General Surgery
816-4629
P. R. Cunningham, MD
William H. H. Chapman III, MD
M. B. Foil, MD
D. R. Lannin, MD
K. G. MacDonald, MD
P. G. Meade, MD
T. N. Patselas, MD
W. J. Pories, MD
L. Tafra, MD
R. W. Youngblood, MD

Plastic Surgery 816-5291
W. A. Wooden, MD
J. C. Benacci, MD

Surgical Curriculum
816-5262
S. S. Cox, PhD

Surgical Oncology
816-5418/4629
D. R. Lannin, MD
W. J. Pories, MD
L. Tafra, M.D.

Thoracic Surgery
816-4629
W. R. Chitwood, Jr., MD
J. R. Elbeery, MD
T. C. Koutlas, MD
J. E. Miller, MD
J. F. Moran, MD
W. J. Pories, MD
J. M. Williams, MD
R. W. Youngblood, MD

Trace Element Center
816-2963
R. H. Maier, PhD
W. J. Pories, MD

Transplantation
816-2614
C. E. Haisch, MD
P. R. Cunningham, MD
K. M. Verbanac, PhD

Trauma/Critical Care
816-4299
P. R. Cunningham, MD
M. B. Foil, MD
C. E. Haisch, MD
T. N. Patselas, MD

Vascular Surgery
816-4667
C. S. Powell, MD
W. M. Bogey, MD
D. H. Deaton, MD

Greenville,
North Carolina
27858-4354

Hello,

My name is _____. I am working for the Leo W. Jenkins Cancer Center/ECU School of Medicine collecting census information for a breast cancer research project. We will be talking with women ages 19 and over in Pitt and Wilson Counties to help us encourage women to learn about breast cancer.

As the first step in this project, we need to learn what women in these counties know and what their opinions are about breast cancer. We are asking for your help.

This block (or area) was chosen randomly from those in this county using North Carolina census information. I am going house-to-house in this block (area) to identify houses where women over age 19 live. I have just a few questions that I hope you will answer today. Also, I am asking if you will agree to a visit later in your home with a woman to discuss your ideas and opinions about breast cancer. If you agree to the visit, the information you provide today will help someone contact you to set up an appointment for the visit.

All of the information we collect will be kept confidential. Also, again, this block and your household were selected randomly.

If you have any questions, you may call the project manager, Frances Swanson, MS at (919) 816-5418. Thank you for your help in this very worthwhile project.

DATA COLLECTION HINTS

1. Plan your visits. Be sure to take your instruction sheets, data collection sheets, maps, pens, and other information with you.
2. Be familiar with the project so you can explain why the information is being collected.
3. Develop your own introductory statements, using your own style, to introduce yourself, tell why you are there, and what information you will be collecting.
4. Be courteous and pleasant. You are the first person from this project these women are meeting. The success of our data collection and the project depends on you!
5. Wear comfortable and sensible clothing.
6. Make your visits during daylight hours and avoid making visits on Sundays.
7. Lock your purse and other belongings in the trunk of your car. Carry a minimal amount of cash.
8. Use the maps to become familiar with the area ahead of time.
9. Fill out the data collection forms neatly and completely according to instructions.
10. It may be necessary to return to the block area on the map more than once to canvas the block completely and identify all women 19 and over living in the block.
11. If you find a woman who has had breast cancer, please complete the census form for that household anyway, being certain to mark "yes" under the question about breast cancer.
12. Under no circumstances should you jeopardize your safety.
13. If you have any questions, call the project manager, Frances Swanson, MS at (919) 816-5418.

INSTRUCTIONS FOR COMPLETING CENSUS FORMS

Complete a "Preliminary Household Interview" form for **each** woman, age 19 and over, African-American or White, in each household.

Write your name and ID number in the census worker space.

Record the county, community, and tract/block number. This information can be found on the census maps that you have been given.

For **each woman 19 and over living in the household**, record:

- first name, last name
- complete street address including lot or apartment number
- city, state, zipcode
- age (in years) and date of birth (month, day, year)
- race
- breast cancer question
- area code and telephone number
- best day of week and best time of day (may check multiple responses)

Use the black felt tip pen which was provided. Print neatly in capital letters so each letter fits in a square.

Ask if there is a possibility that the address will be changing in the near future and write the new address at the bottom of the form (NOT in the box).

Write **clear** directions on how to find the residence!! For example, South on Hwy. 43 to Worthington's Crossroads, after X roads, second house on right, brick with white trim. Please be sure written directions are **neat and easy to read**.

Tell the woman that someone will contact her later this summer to make an appointment for the longer visit, which will last an hour or more.

Remember, the information you record will be used to contact these women again so they can be interviewed for the study. The interviewer will have no other information or directions except what you have recorded. Be as clear and specific as possible.

Please check and **re-check** each form for accuracy and completeness.

Please turn your completed "Preliminary Household Interview" forms in to the designated person at your county Health Department.

Culturally Based Intervention for
Breast Cancer In
Rural African Americans

05-97

Name: _____ Soc. Security No.: ____-____-____

Mailing Address: _____
(Street, P.O. Box, Rural Route)

(City, Town) (Zip Code)

(Telephone Number)

Employer's Address (If Employed): _____
(Name or Company)

(Address)

Block/Tract No(s): _____

WORK DONE

<u>Date</u>	<u>Beginning Time</u>	<u>Ending Time</u>	<u>Total Hours</u>	<u>Census Forms Completed</u>	<u>Miles Driven</u>
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____

Total Hours for Reporting Period: _____ Total Miles: _____

Signature: _____

Your signature certifies that the hours reported are accurate. Please allow up to 5 weeks for your payment to be processed.

**EAST CAROLINA BREAST CANCER AWARENESS PROGRAM
ADVISORY BOARD
AGENDA
AUGUST 18, 1998**

WELCOME

INTRODUCTION

VIDEO: *To Live On*

PROJECT BACKGROUND AND GOALS

PUBLIC SERVICE ANNOUNCEMENTS

IDEAS AND SUGGESTIONS

- INVITATION LIST FOR KICK-OFF
- EVALUATION FORM FOR PSA's
- OTHER IDEAS - HOW TO REACH COMMUNITY

Kimberly Johnson ECU Physicians 1204 E. Firetower Td. Greenville, NC 27858 Linda Mayne Leo W. Jenkins Cancer Center Greenville, NC 27835 Marion Gorham Wilkes 1108 W 5th St Greenville, NC 27834 Linner W. Griffin, EdD ECU Dept. of Social Work Greenville, NC 27858 Ceylon Rowland, MD Women's Health Center 704 W. H. Smith Blvd. Greenville, NC 27834 E. C. Land, MD 2315 Executive Park West Greenville, NC 27834 Julius Mallette, MD ECU Dept of Ob/Gyn Greenville, NC 27858 Julia Davis 501 Contentnea Street Greenville, NC 27834 Dorothy Josey, Chaplain Cornerstone Baptist Church Stantonsburg Rd. Greenville, NC 27834 Connie Clark, RN Pitt County Health Dept. 205 Government Circle Greenville, NC 27834	Earnestine Haselrig 1100 Fairfax Avenue Greenville, NC 27834 Donald Ensley, PhD ECU Dept. of Community Health Greenville, NC 27858 Rhonda Jordan Pitt County Mental Health 203 Government Circle Greenville, NC 27834 Rev. Sidney Locks 1095 Allen Rd. Greenville, NC 27834 Scott Wells ECU Office of Development Greenville, NC 27834 Alphonsus Okoli, MD Grifton Internal Medicine 5477 Hwy 11 Grifton, NC 28530 Inez Fridley 802 River Dr. Greenville, NC 27834 Marlene Farrior 219 N. Main Street Farmville, NC 27828 David White, EdD School of Health & Human Performance ECU Greenville, NC 27834 Phyllis Horns, Dean ECU School of Nursing Greenville, NC 27834	Chaplain Randy Curtis 100 Tobacco Rd., D-6 Greenville, NC 27834 Minerva D. Freeman 205 Government Circle Greenville, NC 27834 Linda Bond 106 Willow Dr. Williamston, NC 27892 Carmen Vincent 3256 Landmark St. Greenville, NC 27834 Marian Carson PCMH PO Box 6028 Greenville, NC 27835 Edward Treadwell, MD Rheumatology, Brody 3E-111 ECU Dept of Medicine Greenville, NC 27858 Terry Shank 1215 Drexel Lane Greenville, NC 27858 Donna Harris 501 Oakdale Dr. Ayden, NC 28513 Randy Royal, Pastor Philippi Church of Christ 1610 Farmville Blvd. Greenville, NC 27834 Jennifer Congleton PCMH, Service Excellence Greenville, NC 27835
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**EAST CAROLINA
BREAST CANCER
AWARENESS PROGRAM
(EC-BCAP)**

**ADVISORY BOARD MEETING
TUESDAY, AUGUST 18, 1998
WILLIS BUILDING**

***THE EAST CAROLINA BREAST CANCER AWARENESS PROGRAM
(EC-BCAP) IS AFFILIATED WITH THE LEO W. JENKINS CANCER
CENTER AND EAST CAROLINA UNIVERSITY.***

BACKGROUND:

- | | |
|-----------|--|
| 1988-1993 | American Cancer Society funded project to identify, "Psychosocial Factors Delaying Breast Cancer Presentation" |
| 1996-2000 | Department of Defense Breast Cancer Project: East Carolina Breast Cancer Awareness Program (EC-BCAP) |

We have studied the underlying reasons for late breast cancer presentation in women and found two distinct but complimentary causes. The first is lack of breast screening with physical exam and mammography. The second is patient initiated delay caused by aberrant cultural and psychosocial attitudes and beliefs. The goal of the current project is to develop methods to encourage earlier detection of breast cancer. To accomplish this, a multi-disciplinary team of physicians, education specialists, anthropologists, and sociologists will develop and test a unique intervention- the first ever to specifically target both of the underlying causes of advanced stage of breast cancer.

EC-BCAP is a community-wide effort to promote breast screening and alter those beliefs and practices that predispose to delayed presentation. The efforts are organized into three phases:

Phase I- Pre-Surveys

Phase II- Intervention

Phase III- Post-Surveys

PHASE I- PRE-SURVEYS

- **Census surveys** were done to find women residents in Pitt County and Wilson County for the cohort surveys. Wilson County was chosen as the control county because of similar demographic characteristics to Pitt County.
- **Cross-sectional and cohort survey** of 1200 women in Pitt County and Wilson County comparing the strengths of these specific beliefs and self-reported breast cancer screening and symptom recognition behavior.

PHASE II- INTERVENTION

- **Kickoff Educational Symposium** will be held October 6th for Breast Cancer Awareness Month to draw attention to minority health issues and to make the medical community and the public aware of the upcoming intervention.
- **Speaker's bureau** to provide educational programs in churches, worksites, civic groups, and senior centers.
- **Media campaign** of educational messages will be done through television, newspapers, and radio.
- **Disbursement of educational materials** such as brochures and posters to be set up in doctor's offices, hair salons, churches, grocery stores, etc.
- **Ob-Gyn office program** to reach older women through their younger female relatives by verbal instruction and encouragement.

PHASE III- POST-SURVEYS

- **Cross-sectional and cohort survey** of the previous 1200 women to determine the effectiveness of the intervention
- **Sampling of 500 additional women** to be interviewed to control the testing effect.

6 MAIN BELIEFS

- ***Over reliance on God.*** The message will be that God works through doctors to cure breast cancer and other diseases and that God would want a woman to get a mammogram or to seek medical care early for a lump in the breast. It will be particularly important to enlist the help of the local clergy.
- ***Fatalism.*** The message will be that for certain diseases a person's actions really make a difference, and that breast cancer is one of those diseases.
- ***Air causes the cancer to spread.*** The message will be that cutting a cancer or exposing it to air does not cause it to spread, and in particular, this is not a reason to delay removing a lump.
- ***The man would not be supportive.*** The message will be that a breast lump is something which can and should be discussed openly with a husband or male partner, and that it is a problem which partners can solve together.
- ***A lump is not serious if it does not hurt.*** A factual message will convey that a lump or knot is serious even if it does not hurt, and that a woman should not wait until it hurts to seek help.
- ***Belief in alternative treatments other than surgery.*** Messages will be developed that promote surgical removal of breast lumps as the simplest, most logical solution to the problem.

1

OCTOBER 6, 1998

6:00-8:00 PM GREENVILLE HILTON

[illegible]

**BREAST CANCER AWARENESS PROGRAM
PUBLIC SERVICE ANNOUNCEMENT
EVALUATION FORM**

1 = MOST EFFECTIVE
2 = EFFECTIVE
3 = LEAST EFFECTIVE

<u>ACTOR</u>	<u>TOPIC</u>	<u>LENGTH</u>	<u>SCORE</u>	<u>COMMENTS</u>
CLIFTON DAVIS	FEAR	30 SECONDS	_____	_____
CLIFTON DAVIS	FEAR	10 SECONDS	_____	_____
CLIFTON DAVIS	DELAY	30 SECONDS	_____	_____
CLIFTON DAVIS	DELAY	10 SECONDS	_____	_____
ELAINA REED HALL	AIR	30 SECONDS	_____	_____
ELAINA REED HALL	AIR	10 SECONDS	_____	_____
ELAINA REED HALL	GOD'S WORK	20 SECONDS	_____	_____
DAN MARTIN	FEAR	30 SECONDS	_____	_____
DAN MARTIN	AFRAID	30 SECONDS	_____	_____
DAN MARTIN	AFRAID	10 SECONDS	_____	_____
KENNY BLANK	GRANDMOTHER	30 SECONDS	_____	_____
KENNY BLANK	GRANDMOTHER	10 SECONDS	_____	_____

BREAST CANCER AWARENESS PROGRAM
PUBLIC SERVICE ANNOUNCEMENT
EVALUATION FORM

ROZ RYAN	AFRAID	30 SECONDS	_____	_____
ROZ RYAN	AFRAID	10 SECONDS	_____	_____
ROZ RYAN	FEAR	30 SECONDS	_____	_____
ROZ RYAN	FEAR	10 SECONDS	_____	_____
ANNA MARIA HORSFORD	AIR	30 SECONDS	_____	_____
ANNA MARIA HORSFORD	AIR	10 SECONDS	_____	_____
ANNA MARIA HORSFORD	GOD'S WORK	20 SECONDS	_____	_____

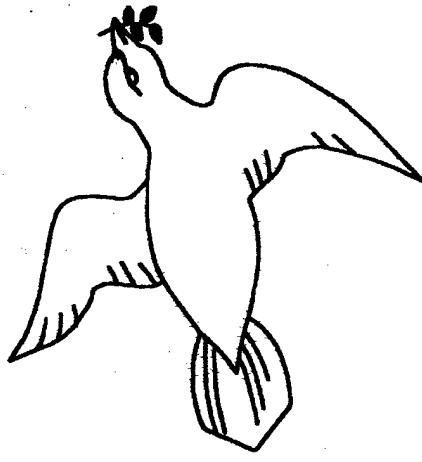
❖ 1 out of every 8 women will get breast cancer at some time in her life

❖ There are about 180,000 new cases and about 45,000 deaths from breast cancer in the United States each year

❖ About 200 new cases are treated each year at the Leo W. Jenkins Cancer Center

❖ The risk of getting breast cancer is about the same for white women and African American women

❖ A woman's risk of breast cancer starts at about age 30 and gets higher the older she gets



Please contact Frances Swanson or Kimberly Best at (252) 816-5418 between the hours of 8:00a.m. - 5:00p.m., Monday through Friday with any questions or to schedule a program.

EAST CAROLINA BREAST CANCER AWARENESS PROGRAM

The East Carolina Breast Cancer Awareness Program (EC-BCAP) is affiliated with the Leo W. Jenkins Cancer Center and East Carolina University.

**"STRENGTHENING OUR
COMMUNITY AGAINST
BREAST CANCER"**

Breast cancer is not a death sentence. If it is found early, women have an excellent chance of cure.

One reason women sometimes die from breast cancer is that they go to the doctor too late after finding a problem with their breast. Certain superstitions are important reasons that cause lack of screening or delay.

The East Carolina Breast Cancer Awareness

Program is a community-wide effort to educate Pitt County women about the importance of breast cancer screening and early detection in treating this disease.

Our goal is to decrease the number of women dying from breast cancer in Pitt County. Our aim is to promote breast screening and alter those beliefs and practices that cause women to go to the doctor with late stage disease. This will be done by using:

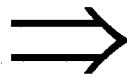
- educational messages through television, radio, and newspaper
- brochures at stores, salons, and workplaces
- educational programs for churches, schools, civic groups, and businesses conducted by trained breast cancer experts
- doctor's office programs
- a documentary video, *To Live On*, of local women talking about their breast cancer experiences

We need you to schedule a time for us to come to your church, business, or civic group to do a program. We also need your help in displaying and distributing educational materials in various places where the women in Pitt County can read them.

Please tell others about the **East Carolina Breast Cancer Awareness Program (EC-BCAP)** and help spread the word about how we can beat this disease.



**WELL
THEY
ARE**



WRONG

If you have any questions or concerns about breast cancer, please call 816-5418 between the hours of 8:00 a.m. -5:00 p.m., Monday through Friday.

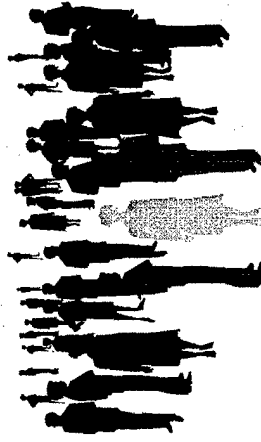
**Has anyone
ever told
you?**

**-That air getting
to a cancer will
make it spread?**

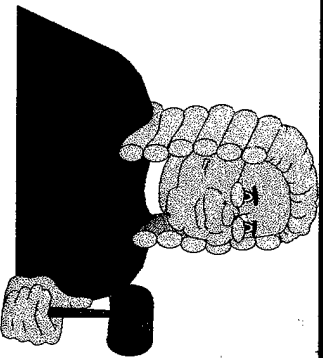
OR

**-That cutting on
a cancer will
make it grow?**

The East Carolina Breast
Cancer Awareness Program
(EC-BCAP) is affiliated with
the
Leo W. Jenkins Cancer Center
and
East Carolina University.



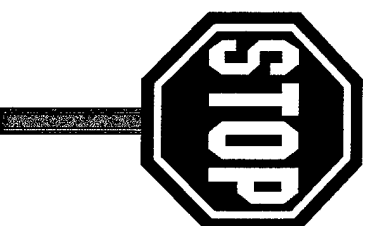
THE TRUTH IS THAT:



✓ A cancer is a group of cells that are growing out of control.

✓ Once a small cancer forms, it is only a matter of time until it grows and spreads.

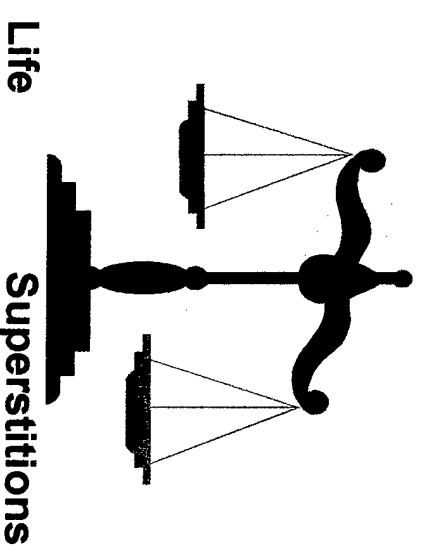
The **BEST** way to **STOP** a cancer from spreading is to remove it from the body as soon as possible.



SURGERY is the only sure way to keep a cancer from spreading. **Early removal** of a lump is your best chance to **BEAT** cancer.

So remember, if you find a knot or lump in your breast, talk to your doctor about it right away. Don't be scared by what other people may tell you.

Your Life Is More Important Than Superstitions.



D2 The Daily Reflector, Thursday, September 17, 1998

Body & MIND

Breast cancer

The East Carolina Breast Cancer Awareness Program, sponsored by the Leo W. Jenkins Cancer Center, is hosting a kickoff reception at 6:30 p.m. Oct. 6 at the Greenville Hilton.

Sylvia Dunnavant, author of "Celebrating Life: African-American Women Speak Out About Breast Cancer," will speak.

A new documentary video, "To Live On," which features local women talking about their experiences with breast cancer, will be shown.

The program is a community-wide effort to educate the public on the importance of breast screening and the effectiveness of early detection in treating the disease.

Call 816-5418 by Sept. 30.

You are invited to attend the

East Carolina

Breast Cancer Awareness Program

Kickoff Reception

Greenville Hilton Inn

Tuesday, October 6, 1998

6:30 pm

Refreshments
RSVP by September 30
252.816.5418



LEO W. JENKINS CANCER CENTER
University Health Systems of Eastern Carolina

The East Carolina Breast Cancer Awareness Program is a community-wide effort to educate Pitt County women about the importance of breast cancer screening and the effectiveness of early detection in treating this serious disease. At the reception, we will announce plans for a year-long educational program and premiere our new video, *To Live On*, featuring local women talking about their experiences with breast cancer. Sylvia Dunnavant, inspirational author of *Celebrating Life: African-American Women Speak Out About Breast Cancer*, will speak at the event. Please join us for this exciting evening and help support our efforts to fight breast cancer in Pitt County.

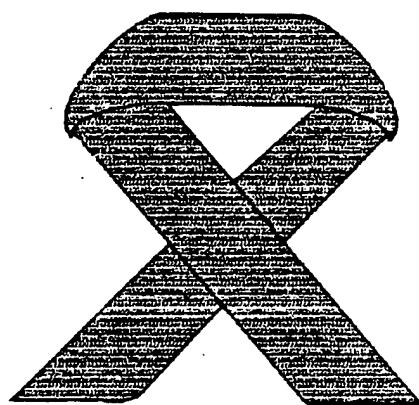
Community Advisory Board

Linda Bond	Donna Harris	Randy Royal
Marian Carson	Ernestine Haselrig	Ceylon Rowland
Connie Clark	Phyllis Horns	Terry Shank
Jennifer Congleton	Rhonda Jordan	Anna Shappley
Randy Curtis	Dorothy Josey	Edward Treadwell
Julia Davis	E. C. Land	Carmen Vincent
Phyllis DeAntonio	Sidney Locks	Scott Wells
Donald Ensley	Julius Mallette	David White
Minerva Freeman	Linda Mayne	Marian Gorham
Linner W. Griffin	Lois Reddrick	Wilkes

PINK RIBBON WALK

CAROLINA EAST MALL

OCTOBER 3, 1998
ACTIVITIES FROM
10:00 AM - 4:00 PM
WALK BEGINS AT 11:00 AM



**THE PINK RIBBON IS A SYMBOL OF
HOPE FOR A CURE FOR BREAST
CANCER AND A REMINDER OF THE
NEED FOR EARLY DETECTION.
COME JOIN US AS WE KICK OFF
BREAST CANCER AWARENESS
WEEK!**

The Ladies of
SIGMA GAMMA RHO
Sorority, Inc.

Present

**BREAST
CANCER
AWARENESS**

WHEN: Thursday, September 24, 1998

WHERE: Mendenhall Student Center
Multipurpose Room

Time: 7:00pm

The East Carolina Breast Cancer Awareness Program is a community-wide effort to educate Pitt County women about the importance of breast cancer screening and the effectiveness of early detection in treating this serious disease. At the reception, we will announce plans for a year-long educational program and premiere our new video, *To Live On*, featuring local women talking about their experiences with breast cancer. Sylvia Dunnavant, inspirational author of *Celebrating Life: African-American Women Speak Out About Breast Cancer*, will speak at the event. Please join us for this exciting evening and help support our efforts to fight breast cancer in Pitt County.

You are invited

to attend the

East Carolina Breast Cancer Awareness Program Kickoff Reception

Greenville Hilton Inn

Tuesday, October 6, 1998

6:30 pm

Refreshments

RSVP by September 30 252.816.5418

www.uhseast.com

LEO W. JENKINS CANCER CENTER
University Health Systems of Eastern Carolina

East Carolina Breast Cancer Awareness Program Community Advisory Board

Linda Bond	E. C. Land
Marian Carson	Sidney Locks
Connie Clark	Julius Mallette
Jennifer Congleton	Linda Mayne
Randy Curtis	Lois Reddick
Julia Davis	Randy Royal
Phyllis DeAntonio	Ceylon Rowland
Donald Ensley	Terry Shank
Minerva Freeman	Anna Shappley
Linner W. Griffin	Edward Treadwell
Donna Harris	Carmen Vincent
Ernestine Haselrig	Scott Wells
Phyllis Horns	David White
Rhonda Jordan	Marian Gorham Wilkes
Dorothy Josey	

The Leo W. Jenkins Cancer Center is part of University Health Systems of Eastern Carolina, which includes Pitt County Memorial Hospital, East Carolina University School of Medicine, private practice physicians and other health affiliates.

The Leo W. Jenkins
Cancer Center

UNIVERSITY MEDICAL CENTER OF EASTERN CAROLINA-PITT COUNTY

Date: June 15, 1998

To: Leaders of Pitt County Churches and Civic Organizations

From: Donald R. Lannin, MD, Director *Don Lannin*

Re: Breast Cancer Education Program available for distribution in Fall 1998

For the past eight years, a group of physicians and faculty at ECU have been researching the reasons why women often delay seeking treatment for breast cancer in eastern North Carolina. In October 1998 we will launch a year-long breast cancer awareness initiative in Pitt County. As part of our efforts, we are offering to present an educational program about breast cancer to churches and civic groups in Pitt County. The centerpiece of our program is a 30 minute video, *To Live On*, which we filmed with six eastern NC women of different ages and ethnic backgrounds with breast cancer. These women discuss their experiences with the disease and its treatment, their hope and fears, and their reliance on family, church members and health professionals for support. This video also features a number of local physicians discussing the current facts about breast cancer and its treatment.

We would be pleased to provide a trained speaker for your church or civic group meeting. This speaker would present a brief introduction to the video, show the video, and then lead a discussion and answer questions about breast cancer for those in attendance. It is our hope that we can present this program to every church and civic group in Pitt County within the next year in order to increase awareness among women about the need for regular screening for breast cancer.

We know that many church groups and organizations plan their yearly calendar of meetings and events in the summer. If you would be interested in scheduling our program on breast cancer during the 1998-99 year or if you would like additional information, please contact Frances Swanson, project manager, at (252) 816-5418. There is no charge for this presentation which we are offering as a public service to the community.

Pitt County
Memorial Hospital

East Carolina University
School of Medicine

Private Practice
Physicians

East Carolina University
School of Medicine

525 Moye Boulevard
Greenville, North Carolina
27858-4354

1-800-223-9328
919-816-5418 Phone
919-816-5775 Fax

DRAFT



SPEAKER'S BUREAU TRAINING MANUAL

*The East Carolina Breast Cancer Awareness Program is affiliated with the Leo W. Jenkins Cancer
Center and East Carolina University*



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PROJECT PERSONNEL

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Director, Leo W. Jenkins Cancer Center
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(919) 328-4839

Jim Mitchell, Ph.D., Co-Investigator
Professor, ECU Dept. of Sociology
(919) 816-2793

Lorraine Tafra, M.D., Co-Investigator
Assistant Professor, ECU Dept. of Surgery
(919) 816-5418

Linda Pololi, M.D., Health Education and Communication
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Professor, ECU Dept. of Surgery
(919) 816-2148

Frances Swanson, MS, Project Manager
Research Associate, Dept. of Surgery
(919) 816-5418

Kimberly Best, R.H.Ed., Health Educator
Social Research Assistant, ECU Dept. of Surgery
(919) 816-5418



PROJECT GOAL

The major reason that some women in our region have poor survival from breast cancer is that they present with advanced stage disease. 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 goal of this project is to develop methods to encourage earlier detection of breast cancer in an area. A community-wide intervention is scheduled to begin in early 1998 in an attempt to promote breast screening and alter those cultural beliefs and practices that may cause some women to delay getting treatment. The intervention will utilize educational messages through television, radio, and newspaper; educational programs conducted through local churches, businesses and schools; and a unique program where older women are reached through their younger relatives who are seeing Ob-Gyn physicians.



WOMEN AND BREAST CANCER

East Carolina Breast Cancer Awareness Program



❖ **INCIDENCE**

Breast cancer is the most frequently occurring cancer in women, both in North Carolina and the United States. It is also the second leading cause of cancer death in women in North Carolina. There are about 180,000 new breast cancer cases diagnosed in the United States each year. Each year approximately 45,000 women die from breast cancer.

Facts about Breast Cancer

- Approximately one in eight women or 12.6% will get breast cancer sometime during her life (based on 100 years of life expectancy).
- Eighty percent of women who develop breast cancer have no family history of the disease.
- Although the risks of getting breast cancer is about the same for white women and African American women, more African American die from breast cancer.
- A woman's risk of breast cancer starts at about age 30 and increases with age.
- About 78% of breast cancer occurs in women over age 50, and over 50% in women over age 65.
- About 200 new cases of breast cancer are treated each year at the Leo W. Jenkins Cancer Center.

❖ **WHO'S AT RISK?**

Risk is the likelihood of getting breast cancer at any time during a woman's life. Every woman is at risk. As a woman ages, her chances of getting breast cancer. Of the cases of breast cancer diagnosed every year, 70% of the patients have none of the risk factors. Therefore having no risk factors should not give you a false sense of security and cause you to ignore the warning.

Primary Risk factors:

- Age
- Having a family history
- Starting menstruation before age 12
- Having your first child after age 30
- Never having a child
- Beginning menopause after age 55
- Past history of breast cancer

Secondary Risk Factors:

- Long-term use of estrogen replacement therapy or use of the birth control pill
- Benign breast disease history
- Alcohol use



Factors that have no proven results are:

- High fat diet
- Weight
- Environmental factors

❖ BREAST CANCER SCREENING

The key to finding breast cancer early is routine screening. Screening is used to look for cancer before there are symptoms of the disease. Breast cancer is 90% curable found in its earliest stages through screening. There are three methods of breast cancer screening which need to be stressed to all women: **mammography, clinical breast exam, and breast self-exam.**

Screening Recommendations

<u>Test:</u>	<u>Age:</u>	<u>Frequency:</u>
Mammography	40	Every year
Clinical Breast Exam (CBE)	20-39	Every 1-3 years
	40 and over	Every year
Breast Self-Exam (BSE)	20 and over	Monthly

Mammography

A **mammogram** is a x-ray picture of the breast taken by a special machine. Mammography is the most effective ways to detect early stage breast cancer. Research shows that the mortality rate would decrease by 30% if every woman in need of a mammogram had one. Mammograms can detect breast cancer up to two years before it can be seen or felt. The American Cancer Society recommends yearly mammograms for all women over the age of forty. There are two types of mammograms: **screening** and **diagnostic**.

Screening mammograms are used to detect unsuspected breast cancer an early stage in a person with no symptoms. This determines whether there is either a low or high probability of breast cancer. When cancer is found early, more treatment options are available and the chance of survival is greater.

Diagnostic mammograms are used to evaluate a patient with a breast mass, other signs or symptoms, an abnormal or questionable screening mammogram, or augmented or reconstructed breasts. This usually correlates with physical findings and symptoms.



A Mammogram Can Find A Lump When It Is Still Small.		
Average size of lumps found by regular breast self-exams	Average size of lumps found by first mammogram	Average size of lumps found by getting regular mammograms
		

Getting a mammogram is a very simple procedure. A mammography technician positions each breast, one at a time, on a small platform. The breast is then compressed by a device called a paddle that is lowered on the breast. Two pictures of the breast are now taken. Another view from the side of the breast is also taken. There will be some pressure on the breast when the [paddle is lowered but it is important to get a clear picture of the breast. Some women say that this pressure can be painful, but most women say that mammograms don't hurt.

Clinical Breast Exam (CBE)

A clinical breast exam is a physical breast exam performed by a doctor or nurse. Regular clinical breast exams are an important part of breast cancer screening. This breast exam can usually find cancers that are smaller than a woman can find in her own breasts. It can also find cancers missed by mammography. Some breast changes, including lumps or knots that can be felt, may not be seen on a mammogram.

All women should have a CBE every 1-3 years and can be scheduled with your regular check-up.

Clinical breast exams can be very effective in finding breast cancer early if it is performed thoroughly. To ensure you are receiving a thorough exam, make sure the practitioner or nurse:

- Palpates both breasts completely (presses into each part of the breast with the pad of the fingers)
- Examines near the collar bone and the armpit area
- Inspects the breasts and asks you to move your arms to make sure there is no dimpling



Breast Self-Exams (BSE)

Women of all ages should examine their breasts once a month. The most important part of examining your breasts is to become familiar with what is normal, so a change or problem can be found. Breast lumps found by women who perform breast exams are usually smaller than those found by women who don't.

Like clinical breast exams, a breast self-exam needs to be done thoroughly. A woman should look for a lump or any unusual thickening that feels different from the rest of her breast. It is important to know the proper techniques to do a thorough breast self-exam. (See next 7 for instructions).

❖ WARNING SIGNALS

Early breast cancer usually does not cause any pain. The first signs of breast cancer can go unnoticed. Most breast changes are not cancer but a woman should see a doctor to be sure especially if they persist.

Some things to watch for:

- A lump or thickening in or near the breast or underarm area
- A change in the size or shape of the breast
- A discharge from the nipple
- A change in the color or feel of the skin of the breast, areola, or nipple
- A lump or other change found during BSE
- Skin dimpling or scaling



BREAST SELF-EXAM GUIDE

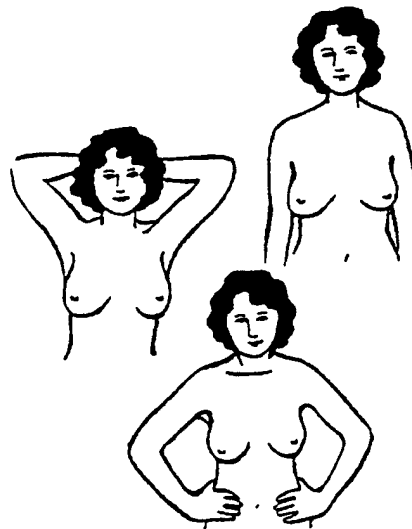
It is best to check your breasts at the same time of each month. The best time is 2-3 days after your period ends. If you are not having periods, pick up a day in the month, like the first day of the month, to examine your breasts.

❖ Looking in the mirror for changes

Without wearing a shirt or bra, stand in front of a mirror with your arms at your side. Look for wetness from your nipples and for skin on your breasts which looks wrinkled or flaky.

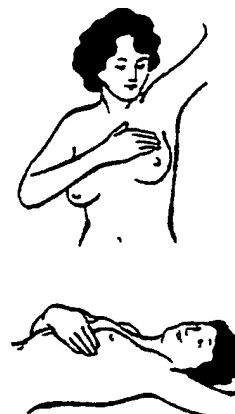
Next hold your hands behind your head and press your hands forward. Look for any change in the shape of your breasts.

Press your hands on your hips. Bend a little forward and pull your shoulders and elbows forward. Again look for any changes in your breasts.



❖ Feeling for lumps

Raise your left arm. Beginning at the outer part of your breast, feel your breasts firmly with 3 to 4 fingers. Press on your breast with the flat part of your fingers and move in small circles. Move around the entire breast toward the nipple. Also feel the area between the breast and underarm and the underarm itself. Raise your right arm and do the same to the other breast.



Lie down flat on your back with your left arm over your head. Put a pillow under your left shoulder. Feel your breast and underarm the same way you did before. Switch arms and do the same.

❖ Check for nipple discharge

Gently squeeze each nipple to see if anything comes out.





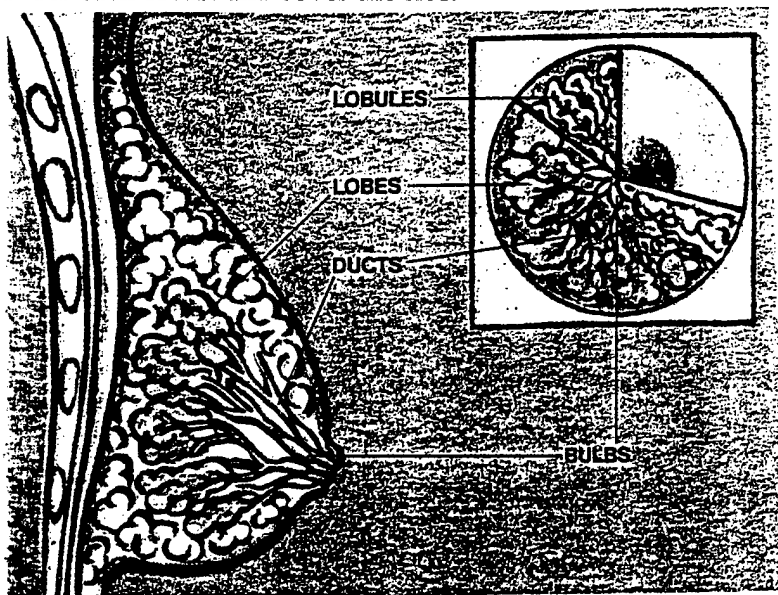
DIAGNOSING BREAST CANCER

East Carolina Breast Cancer Awareness Program



❖ **BREAST TISSUE**

Each breast has 15 to 20 sections, called lobes, each with many smaller lobules. The lobules end in dozens of tiny bulbs that can produce milk. The lobes, lobules, and bulbs are all linked by thin tubes called ducts. These ducts lead to the nipple in the center of a dark area of skin called areola. Fat fills the spaces between lobules and ducts. There are no muscles in the breasts, but muscles lie under each breast and cover the ribs.



❖ **BREAST LUMP AND OTHER CHANGES**

The normal features of the breast can often make them feel lumpy. In addition, from the time a girl begins her period, her breasts undergo regular changes each month. Nearly all breasts develop some lasting changes, beginning when the woman is about 30.

About half of all women will experience symptoms such as lumps, pain, or nipple discharge. These symptoms usually disappear with menopause.

❖ **BENIGN LUMPS**

There are also common benign (non-cancerous) lumps and other changes that occur in the breast. A lump or change in the breast is often not cancer. About 80% of all breast lumps that are tested turn out not to be cancer. The most common are fibrocystic changes, fibroadenomas, cysts, and nipple discharge..

Generalized Breast Lumpiness

Generalized breast lumpiness is also known as “fibrocystic” changes. It is often called a “ropy” or “granular” around the nipple, areola, or upper outer breast. This lumpiness shows up most near middle age because milk-producing tissue recedes and is replaced by softer, fattier tissues. It also occurs during menstruation because extra fluid collects in the breast tissue. The breasts can also feel lumpy during pregnancy, when the milk-producing bulbs swell.



Cysts

Cysts are fluid-filled sacs. They occur most often in women 35 to 50 years of age, and they often enlarge and become tender and painful just before the menstrual period. They are usually found in both breasts. Cysts are often found on ultrasound and are usually treated by drawing the fluid out with a needle in a procedure called fine needle aspiration.

Fibroadenomas

Fibroadenomas are lumps that feel rubbery and can easily be moved around. They are usually painless and found by the women themselves. These are the most common types of lumps in women in their teens and early twenties, and occur more often in African American women. Fibroadenomas look benign on mammograms and are sometimes diagnosed with fine needle aspiration. Doctors often remove them because they can enlarge.

Nipple Discharge

Since the breast is a gland, secretions from the nipple of a mature woman are not unusual. Discharge comes in a variety of colors and textures. Sometimes discharge is caused by infection or inflammation of the breast. Keeping the nipple clean or the use of antibiotics treats benign sticky discharges.

Other Benign Conditions

There are a variety of other conditions that may be diagnosed as benign. These conditions are: fat necrosis, sclerosing adenosis, intraductal papilloma, mammary duct ectasia, and mastitis. They are usually treatable with surgery or antibiotics.

❖ CHECKING FOR CANCER

If you find a lump in your breast, make sure you call your doctor to see if he would like to check it out. The doctor can diagnose the problem in three ways: clinical evaluation, aspiration, or biopsy.

Clinical Evaluation

In a clinical evaluation the doctor will carefully examine your breasts and probably schedule you for a mammogram. Through a CBE, he will determine the location and size of the lump. After he receives the mammogram report, he will decide whether there needs to be any further tests.

Aspiration

If the doctor suspects the lump to be a cyst, he will do an aspiration. Aspiration uses a thin needle and is usually not painful. The needle will draw out fluid from the lump. If it is a cyst, removing the fluid will cause the cyst to collapse and the lump will disappear. If the cysts reappear, the doctor can simply drain it again.



Biopsy

The only sure way to know if a lump is cancerous is a biopsy. This is where tissue is removed by a surgeon and examined by a pathologist. A pathologist is a doctor who specializes in identifying tissue changes that look like a disease, including cancer. Doctors will biopsy a lump that is distinct and persistent. Tissue samples for biopsy can be obtained either with surgery or with needles. The choice of biopsy depends on the location and nature of the lump. In many cases, the diagnosis will be clear-cut.



TREATING BREAST CANCER

East Carolina Breast Cancer Awareness Program



❖ TREATMENTS

Breast cancer treatment for each woman depends on the type of tumor she has, how large it is, how much the cancer has spread, and to where. There are two types of treatment: local and systemic. Local treatments are used to remove, destroy, or control the cancer cells in a specific area. Local treatments includes breast surgery and radiation.

Systemic treatments include chemotherapy and hormonal therapy.

Local Treatments

Breast Surgery

- Mastectomy is the surgical removal of the breast. There are two types of mastectomy: modified radical mastectomy and simple mastectomy. Modified radical mastectomy removes the breast, the underarm lymph nodes, and the lining over the chest muscles. A simple mastectomy removes only the breast.
- Lumpectomy removes the breast lump. Underarm lymph nodes may be removed to test for possible spread of cancer. Lumpectomy is always followed by radiation.

Radiation Therapy

Radiation therapy is the use of high-energy rays to damage cancer cells and stop them from growing. Surgery is often followed by radiation to destroy any remaining cancer cells. It usually takes 5-6 weeks to complete this therapy.

Systemic Treatments

Chemotherapy is the use of drugs to kill cancer cells. It is called systemic because the drugs enter the bloodstream and travel through the body. A combination of drugs is given by mouth or by injection into a vein or muscle. Chemotherapy is given in cycles: a treatment period followed by a recovery period. It usually lasts 3-6 months.

Hormonal therapy is used to keep cancer cells from getting the hormones they need to grow. This type of treatment can be beneficial to women whose cancer cells have estrogen and progesterone receptors. Hormonal therapy is systemic because it can also affect cancer cells throughout the body.



BREAST CANCER RESOURCES

East Carolina Breast Cancer Awareness Program



Leo W. Jenkins Cancer Center

Room 204

P. O. Box 6028

Greenville, NC 27835-6028

(252)816-7867

1-800-223-9328

American Cancer Society

1021-B Red Banks Road

Greenville, NC 27858

(252)321-2836

National Cancer Institute Cancer Information Service

1114 First Avenue

New York, NY 10021

1-800-4-CANCER

National Alliance of Breast Cancer Organizations (NABCO)

9 East 37th Street, 10th Floor

New York, NY 10016

1-800-719-9154

National Women's Health Network

514 10th Street, NW, Suite 400

Washington, DC 20005

(202) 347-1140

Y-Me

212 West Van Burin Street

Chicago, IL 60607-3908

1-800-221-2141



MAKING YOUR PRESENTATION



ROLES AND RESPONSIBILITIES OF A SPEAKER

- **Be familiar with the purpose and importance of the project so you can answer questions about the project.** Many women may want to know how the project came to be. Be able to explain the purpose of the project in your own words. Refer to the brochures if you are unsure.
- **Know how to confront problems and less-than-ideal circumstances.** Most problems will be minor and can be handled as they occur. For example, should an unexpected emergency (i.e. car problems, etc.) result in the delay or cancellation of a scheduled interview, be responsible enough to call and inform the contact person. Also for your benefit, call the contact person 24 hours before the presentation to make sure there have been no changes. More serious problems (i.e. your inability to fulfill your role as a presenter) should be brought to the attention of the project manager, Frances Swanson.
- **Keep what is learned from or about your audience confidential.** Everyone working on this project must maintain confidentiality. All information obtained during the presentation that concerns the audience or their families is privileged information. Information should not be shared with your family, friends, or other presenters. The information may only be shared with the project personnel listed on page 3. We expect all presenters to follow this rule.
- **Be attentive to your appearance.** Your appearance is important to a successful presentation.. Try to dress in the middle range between very formal and very informal. We want you to be comfortable, but we also want the audience to feel comfortable around you. Dressing too formally (i.e. business suits, etc.) may intimidate some people or make them feel inadequate. Dressing too informally (i.e. torn or stained clothing, old or faded sweat pants, T-shirts, etc.) may offend others or cause them to doubt your professionalism. Find out from your contact person for the group about what you should wear. Also be advised that certain personal habits such as smoking and gum chewing may turn people off. Do not engage in such activities once you arrive at your destination.
- **Put the audience at ease so that she will feel free to ask questions.** The best way to do this is to be and feel relaxed. Show a compassionate attitude and an interest in the audience's concerns. Although it is your responsibility to listen attentively, you should always maintain a certain degree of personal distance.



GETTING READY FOR THE PRESENTATION

Scheduling a Presentation

One person from the office personnel will call you to see if you can do the program.

This person will provide you with:

- the name of the group
- contact person
- address
- date
- time

If the time is convenient for you, you are to call the contact to confirm the presentation.

You will need to let the contact know what you need for the program, i.e. VCR, and any other materials.

Things To Take To The Presentation

1. VCR tape
2. Contact form
3. Name Tag
4. Pencils
5. Evaluation forms
6. Brochures

THE PRESENTATION OUTLINE

- I. Introduction
 - A. Who are you?
 - B. What is EC-BCAP?
- I. Video
 - A. Video Contents
 - B. Show the Video
 - C. Response to the Video
- I. Questions
 - A. Questions from audience
 - B. Brochure Reference
- I. Evaluation
 - A. Evaluation Questionnaire
 - B. Contact Form

EC-BCAP PRESENTATION CONTACT FORM

Speaker: _____

Contact: _____

Group: _____

Place: _____

Time: _____

(Start)

(Finish)

Participants: **#** _____

Questions Asked:

Problem Encountered:

Additional Comments:

EC-BCAP EVALUATION FORM

Please fill out this evaluation. This will help us to keep improving our program. We do not need your name because it is confidential.

Group Name: _____

Date: _____

PLEASE CIRCLE YES OR NO

Could you understand the speaker?	YES	NO
Was the speaker Professional?	YES	NO
Did she answer any questions?	YES	NO
Did you enjoy the video?	YES	NO
Could you understand the video?	YES	NO
Before now, had you heard other breast cancer stories?	YES	NO
Would you recommend the video to someone?	YES	NO

Please answer all of the following questions:

What did you like the most about the presentation?

What did you like the least?

After watching the video, what are your thoughts on breast cancer?

If you found a lump or knot in your breast, what would you do?
