

AWARD NUMBER DAMD17-97-1-7312

TITLE: Breast Health Belief Systems Study

PRINCIPAL INVESTIGATOR: Mary P. Williams

CONTRACTING ORGANIZATION: Morehouse School of Medicine
Atlanta, Georgia 30310

REPORT DATE: August 1999

TYPE OF REPORT: Annual

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

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REPORT DOCUMENTATION PAGE

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1. AGENCY USE ONLY (Leave blank)	2. REPORT DATE August 1999	3. REPORT TYPE AND DATES COVERED Annual (14 Jul 98 - 13 Jul 99)	
4. TITLE AND SUBTITLE Breast Health Belief Systems Study		5. FUNDING NUMBERS DAMD17-97-1-7312	
6. AUTHOR(S) Mary P. Williams			
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Morehouse School of Medicine Atlanta, Georgia 30310 mary@link.msm.edu		8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012		10. SPONSORING / MONITORING AGENCY REPORT NUMBER	
11. SUPPLEMENTARY NOTES			
12a. DISTRIBUTION / AVAILABILITY STATEMENT Approved for public release; distribution unlimited		12b. DISTRIBUTION CODE	
13. ABSTRACT (Maximum 200 words) The Morehouse School Medicine is conducting the Breast Health Belief Systems Study, a multi-institutional project. This study was designed to address the issues surrounding constructing effective health promotion messages in regard to breast cancer for African American women who live in the rural South. The hypothesis underlying this research is that a breast health promotion approach that is based in specific belief systems among three disparate African American rural populations of low socioeconomic status (SES) will motivate increased compliance to recommended breast cancer screening schedules and positive shifts in breast cancer screening schedules and positive shifts in breast cancer knowledge and attitudes. This research is proceeding in three phases: (1) qualitative analysis of intra cultural variations in knowledge, attitudes, and beliefs regarding breast disease in 25 low-SES African American women with breast cancer in three distinct areas; (2) use of these ethnographic data to develop a demonstration project for interpersonal delivery of breast health information to 600 breast disease free women; and (3) measurement of effectiveness using lay workers indigenous to the target communities. Phase I has been completed, and Phase 2 is well into its scope of work. Sixty-four African American women participated in the ethnographic survey which resulted in a wealth of data, and new insights into their beliefs and health practices.			
14. SUBJECT TERMS Breast Cancer		15. NUMBER OF PAGES 72	16. PRICE CODE
17. SECURITY CLASSIFICATION OF REPORT Unclassified	18. SECURITY CLASSIFICATION OF THIS PAGE Unclassified	19. SECURITY CLASSIFICATION OF ABSTRACT Unclassified	20. LIMITATION OF ABSTRACT Unlimited

FOREWORD

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Mary Williams 8/19/99

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INTRODUCTION

The Morehouse School Medicine is conducting the Breast Health Belief Systems Study. This study was designed to address the issues surrounding constructing effective health promotion messages in regard to breast cancer for African American women who live in the rural South. The hypothesis underlying this research is that a breast health promotion approach that is based in specific belief systems among three disparate African American rural populations of low socioeconomic status (SES) will motivate increased compliance to recommended breast cancer screening schedules and positive shifts in breast cancer knowledge and attitudes. This research is proceeding in three phases: (1) qualitative analysis of intra cultural variations in knowledge, attitudes, and beliefs regarding breast disease in 25 low-SES African American women with breast cancer in each area; (2) use of these ethnographic data to develop a demonstration project for interpersonal delivery of breast health information to 200 breast disease free women in each area; and (3) measurement of the effectiveness of an educational approach that uses lay workers indigenous to the target communities. The research targets three rural areas: an isolated area of extreme poverty, a poor rural area with access to a metropolitan center; and a poor rural coastal area that provides a range of intra cultural variations. Collaborators are Georgia State University, Fort Valley State University, Albany State University, and Savannah State University. Phase I has been completed and Phase 2 is well into its scope of work. Sixty-four African American women participated in the ethnographic survey which resulted in a wealth of data and new insights.

BODY

STATEMENT OF WORK

Because of unforeseen delays in the recruitment of study subjects and the data collection process, it is projected that an additional six months will be needed to completed this study. Therefore, the work schedule was revised and approved, March, 1999. Figure I shows the revised statement of work. The completion of Phase I and the initiation of Phase II were addressed this project year.

Months	Tasks
10 - 14 (July, 97)	Data gathering, data coding
15	Train new interviewers
16 - 17	Completion of Data Collection
18 - 21	Completion of Data Analysis (End of Phase I
22 - 25	Message Development
26 - 27	Curriculum Development; pilot-testing
28 - 29	Conduct Lay Worker Training
30 - 35	Conduct Intervention, Collect quantitative data
36 - 38	Conduct Follow-up
39 - 40	Analyze Intervention Data
41 - 42 (December, 2000)	Analyze; Finalize Project/write final report

Figure 1: Statement of Work (revised, 3/99)

PHASE 1: Qualitative Analysis of intra cultural variations in knowledge, attitudes and beliefs

It is well documented by previous research that African American women as a whole present to the medical community in more advanced stages of breast cancer than white women. While the incidence of breast cancer is higher in white women the overall mortality rates from breast cancer is higher in African American women. This higher mortality rate is thought to be due to late stage diagnosis and socioeconomic status. Despite this higher mortality rate of breast cancer among African American women, there is limited information published on effective interventions to increase breast cancer awareness and early screening. Research examining the efficacy of health promotion message appeals, content, and channels of delivery has also been very limited in public health research. These research areas as well as those examining the defining variables of cultural sensitivity are almost completely unexplored regarding health promotion efforts specifically targeting low-SES and African American audiences.

For the purposes of this research, culture is defined as a set of interlocking cognitive schemata that construct and give meaning to what people do in their everyday lives. In order to understand how culture works, it is necessary to examine the storage and transmission of information and belief systems shared by a group of people. These strategies are used to guide health-seeking behavior and give it meaning to people's lives. Beliefs are defined as the basic units of thought that establish a relationship between at least two entities. Cognitive beliefs assess the truthfulness or falsify of a given topic. Verbal beliefs are called opinions. Values are beliefs that attempt to determine worth by assigning the moral dimensions of good or bad, right or wrong. Attitudes are a set of beliefs that predispose people to react positively or negatively. They include components of cognition, affect, and intensity. Beliefs that are primitive and rigid in one culture often change in another, and values can change within a cultural over time. Most importantly, beliefs, values, and attitudes are culturally driven.

An understanding and respect of a target group's beliefs, values, attitudes, world views, social organization, and socialization are important factors of cultural sensitivity in health messages. These factors personalize the message through enhance significance, credence, and comprehension, and increase the likelihood of that the target audience will understand and accept the recommendations. A number of factors frustrate the formulation of effective, behavior-changing health communication. Health information and recommendations are traditionally based upon epidemiologic findings that do not often include a broad, in-depth assessment of culturally driven behaviors that are especially prevalent in multiethnic and multi cultural societies. Further, health promotion campaigns usually exhort people to change deeply rooted beliefs and behaviors that have been continually reinforced over a lifetime, and perhaps throughout preceding generations. Social scientists and health communications researchers have held that if health promotion campaigns are to influence the audience as intended, they must be culturally, demographically, and geographically appropriate.

Help-seeking behaviors are, in effect reenactment of cultural models of the social world. Consequently, belief systems from help seeking options and the individual and group evaluation of these options. It should be noted that cultural knowledge is not shared equally throughout a group, and members use diverse sources for their knowledge. Delineating the belief structures of African American women in rural Georgia and their variations is the critical goal of this ethnographic analysis. The principle research objectives of this component of the research was to uncover intra cultural variations in breast cancer knowledge, attitudes, and behavior among low SES African American women who had received a diagnostic of breast cancer in rural Georgia. Qualitatively, this research assumed the following:

1. The more frequently members of rural communities participate in complex, urban systems, the more likely they are to seek preventive, biomedical care.
2. The more closed a cultural system is, the less likely individuals who live within that system are to seek preventive biomedical care.
3. Culturally based belief systems regarding preventive, biomedical care is stronger persuasive agents than access to, or afford ability of preventive care.

Description of Study Population, Study Sites, and Subject Selection: The study population for the ethnographic survey is African American women living in rural South Georgia who have received a diagnosis of breast cancer. Study Subject eligibility criteria were: over age 40, lived in area for past 15 years, low SES (as defined by Georgia Department Of Human Resources, see appendix A).

This research targeted rural counties in south Georgia where similar and distinctly different demographic characteristics exist. These counties generally rank lower than their urban counterparts on conventionally used, measurable indices of quality of life, i.e., poverty, low population density, large geographic expanses, lack of human service-related resources and negative capital follow to urban areas. Three geographic sites of rural south Georgia were drawn to represent southwest, middle and southeast Georgia. Each of these regions contained a historically black college or university (HBCUs) from which graduate level research assistants were selected and trained to conduct the ethnographic interviews. These HBCUs were Albany State University located in the southwest region, Fort Valley State University located in middle region, and Savannah State University located in the southeastern coastal region. Study subjects were recruited from counties within these three sites. As a convenience for data management these sites were named for the HBCU in their region and are referred to by those names throughout the study report. Counties selected for study recruitment were assigned to one of the following site groups: poor and isolated (50 miles or more from a major urban area), poor but located near (within 25 miles of a major urban area), and poor and coastal with a significant cultural variations in population and where traditional African customs are actively practiced. Figure 2 depicts these study sites. Table 1 shows the demographic characteristics of the targeted counties in these sites, and Table 2 the demographics of the women participating in the ethnographic interview.

DATA GATHERING: The methods for collection of data were formal interviewing using an interview schedule and free list and pile sort techniques (see appendix B). Questions were designed to elicit descriptive information for determining the explanatory models, decision models, and cultural domain of the targeted population. For example, respondents were asked about their beliefs about the cause and symptoms of breast disorders, why people have the, what they think about people who have the disease (attitudes), what kind of support they have for managing the disease (use formal and informal systems), the relationship between religion and cancer, and where they learned about the disease and its management. Each respondent was also asked to list the causes, symptoms, and treatments for breast cancer. This technique allowed for an analysis of the cultural limits of breast cancer; its cultural domain was delineated. Pile sorting is a technique that allows for an analysis of similarities of cultural categories used by the samples. Respondents were asked to make judgements about the similarities and characteristics of the causes, symptoms, and treatments for breast cancer.

In addition, a personal and demographic information questionnaire (see appendix B) was administered before the major research instrument. The interview instrument included an extensive narrative chronicling the experiences of each respondent with breast cancer. These interviews were conducted by research assistants trained in qualitative interview methods. In order to ensure that the data collected was an accurate representation of the subjects' views versus the filtered perspectives of the interviewers, each interview was audio taped. These

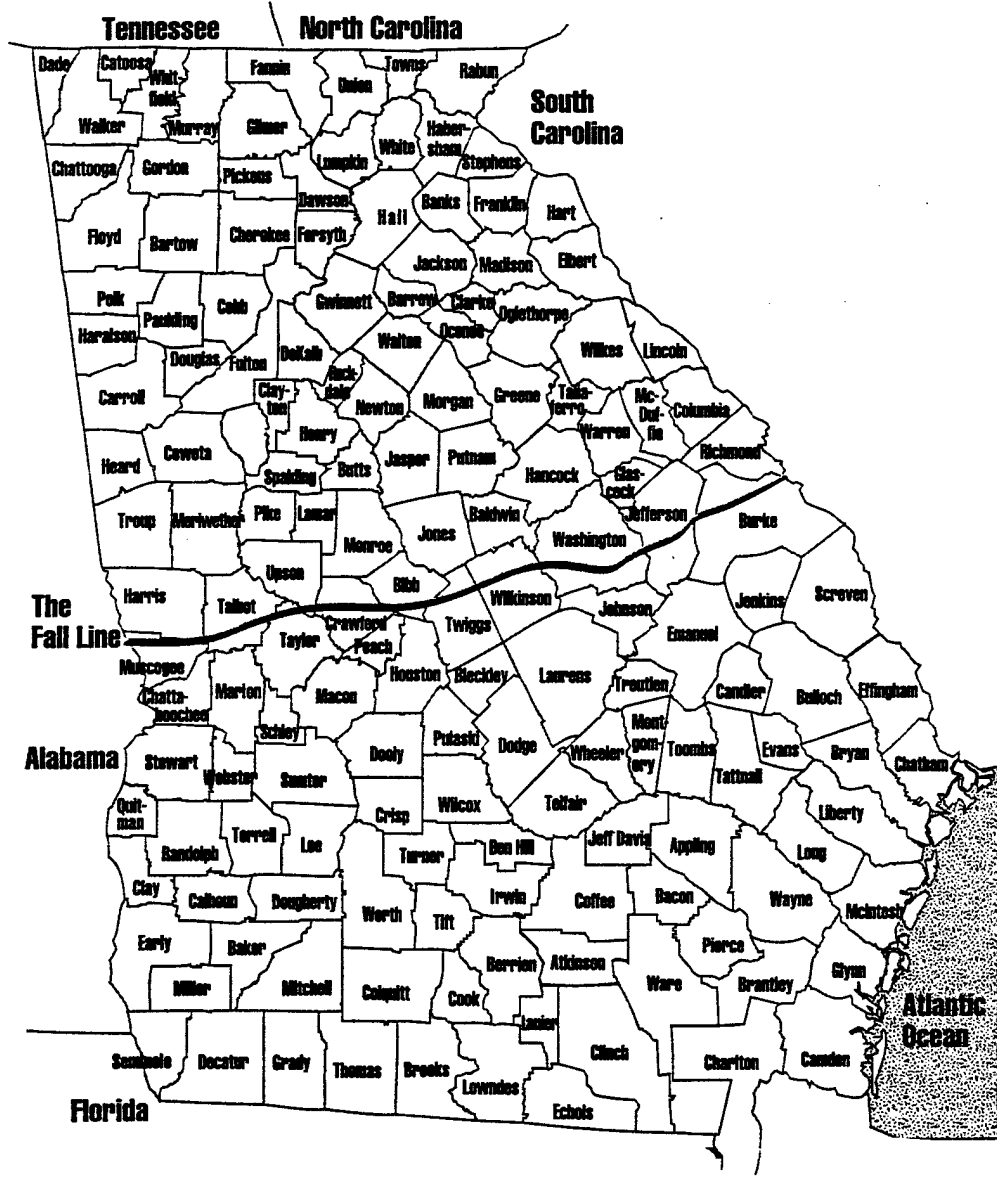


Figure 2: Geographical Sites for Ethnographic Survey

Table 1: Demographic characteristics of counties in three study sites

Counties	Total Population	% Pop. Black	Average Income	% Pop. Income >200% of Poverty Lev.	No. General Doctors	No. Hospital Beds	% Adults with high school dipl only
Baker	3,875	51	18,458	46.5	1	0	53.5
Calhoun	6,606	59	20,698	36.7	3	40	52.2
Dougherty	89,639	50	27,933	54.5	85	334	67.5
Houston	62,924	22	29,348	71.0	59	225	79.5
Liberty	17,569	50	21,643	40.0	5	50	82.0
Monroe	10,991	32	27,708	62.0	5	40	66.0
Peach	15,990	48	25,793	55.0	12	76	68.0
Twiggs	8,222	46	24,158	48.0	9	0	48.0
Worth	14,770	31	23,757	51.0	10	50	53.0

Source: Georgia County Snapshots, Georgia Department of Community Affairs, 1996

Table 2. Demographic Characteristics of Study Sample

Site Respondents	Mean age (range)	Mean Income	Yrs resident	PD	C	MC	PI	M/M	FFS	Oth	num
Fort Valley		\$15,600	33	88	4	8	64	16	8	8	25
Albany		\$16,667	27	84	12	-	52	16	12		25
Savannah		\$15,385	34	57	14	-	43	29	7		14
Total	55 (xx-xx)	15,968	31	77%	10%	8%	53%	20%	9%	8%	64

Years elapsed since diagnosis of breast cancer: Fort Valley=8 yrs; Albany=3 yrs; Savannah=7 yrs

Legend: PI=Private Insurance i.e. PPO, HMO, Indemnity

M/M=Medicaid/Medicare

FFS=Fee for Services

Other=Uninsured/Non Respondent

MC=Military Coverage/Insurance

PD=Private Doctor

C=Clinic

audiotapes were transcribed and used to verify and enhance information collected by the research assistants.

TRAIN NEW INTERVIEWERS: Because of the delay created by having to develop a registry in some of the counties where subjects were recruited, some of the research assistants completed their course of study at the universities and moved out of the study areas. This created the need to recruit and train new interviewers who subsequently completed the interviewing process.

COMPLETION OF DATA COLLECTION: Data collection was completed in month 17 of the study.

Accomplishments: These data collection methods yield 64 completed questionnaires which averaged 15 written pages per subject and 10 to 20 pages of transcriptions from the audiotapes. See Appendix C for sample.

Problems Encountered: The problem encountered in Year One were also experienced in year 2. Because the state database on breast cancer case was not available to this study in some of the counties where the recruitment took place, researchers had to develop a registry of breast cancer cases. This caused a delay in identifying, recruiting and interviewing study subjects. This was particularly true in the Fort Valley area.

DATA CODING AND MANAGEMENT: This process proceeded in four phases: 1) cross-coding the textual and structured data and entering it into the appropriate computer software program; 2) constructing a profile for each research site; 3) constructing demographic, cultural, and behavioral profiles for the subsamples; 4) constructing cultural consensus and decision models for the subsamples; and 5) comparing the subsamples for intercultural and intra cultural concordance and variation.

Field notes were treated as texts, and transcribed and coded. Text coding was done on a weekly basis, using a precoded system worked out in the pilot study, and checked for reliability by requiring that at least two researchers independently code the text, and negotiate any differences referring to the descriptive data collected during the interviews and participant observation. The codes were inserted into the text and matched with those in the semi-structured and structure interviews. Cross coding allow for merging the different types of research techniques.

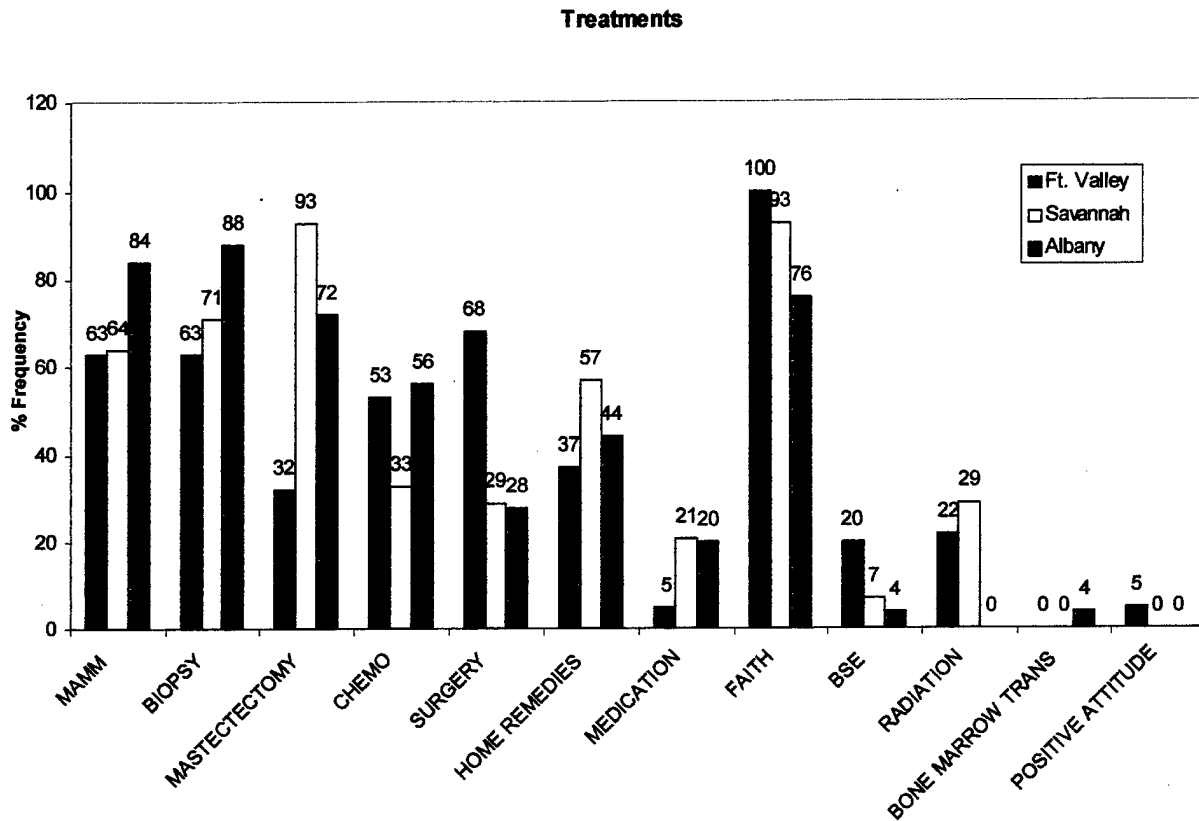
DATA ANALYSIS: Interview data was analyzed by writing summaries for responses to each question for all subsamples. A context analysis for each response included identifying the primary and secondary themes, identifying the most frequent theme for each question, and describing the degree of variation or consensus themes. The goal I for inter-rater reliability was set at 90%. Analysis included constructing a profile of the EMS for the three subsamples, aggregating their responses on the EM interview schedule. A summary of the demographic characteristic of respondents in each subsample, e.g., age, educational level, income, employment, health insurance status, and history of breast disorders and related problems was made for each respondent and subsample. These data were correlated with the subjects's health seeking behavior in both the formal and informal systems.

Cultural consensus model were constructed for each subsample by examining the agreement between respondents on what elements constitute the breast disorder domain. Analysis of the elements of this cultural domain involved algorithmic analysis to create a distance matrix. These relationships are analyzed using cluster analysis and multidimensional scaling, which transform the numbers into a visual representation of the relationships between respondents and among groups of respondents and of the relationships between variables and groups of variables. Cluster analysis was used to analyze the relationship between classification of elements within a specific cultural domain. It allowed for graphic representation of data groupings. Multidimensional scaling was used to represent spatially the elements of a domain and to estimate the number of underlying dimension that organize respondents classification of the data. The Aggregated responses for each group or subsample was analyzed. Intercultural variation was examined by comparing the aggregated response among the subsamples.

Findings: The findings from this ethnographic phase of the study were both confirming of previous research and providing of new insights into the belief structure of rural, southern African American women. A comprehensive analysis report is available and will be submitted with the final report of this study. The following is a summary of the salient as these relate to the three assumptions (hypotheses) that directed the ethnographic survey:

- The belief system of African American women with breast cancer at the three sites in rural Georgia combines traditional and biomedical beliefs, confirming previous studies on breast cancer and belief systems in general among southern African Americans.
- Women at all three sites used the same terminology as medical professional to describe breast cancer, but they do not necessarily share the same meaning of these terms. This finding is significant for understanding the communications processes between health and medical professionals may be hampered by the use of the same terms but not sharing the same meaning, ie, mammography as a treatment whether than a screening tool.
- Home remedies were acknowledged in fifty-seven percent of the respondents at the Savannah site as a form of treatment. Home remedies included garlic, vinegar, tofu, vitamins, nuts fruits, and even marijuana.
- Faith was the top choice for treatment at all sites. The responses clearly opted for a medical treatment with faith as an essential part of that treatment. (see Figure, 3: Explanatory Model for Breast Cancer Treatment).
- The most frequent terminology used to describe symptoms of breast cancer by women in all three sites reflects a biomedical perspective (see Figure 4). However, there were significant differences between sites in motivation to get breasts checked by a doctor. Having pain was the more prevailing motivation for the Fort Valley and Savannah sites. More respondents at the Albany site found lumps without pain than the other sites and this was the most prevailing motivation to visit the doctor.

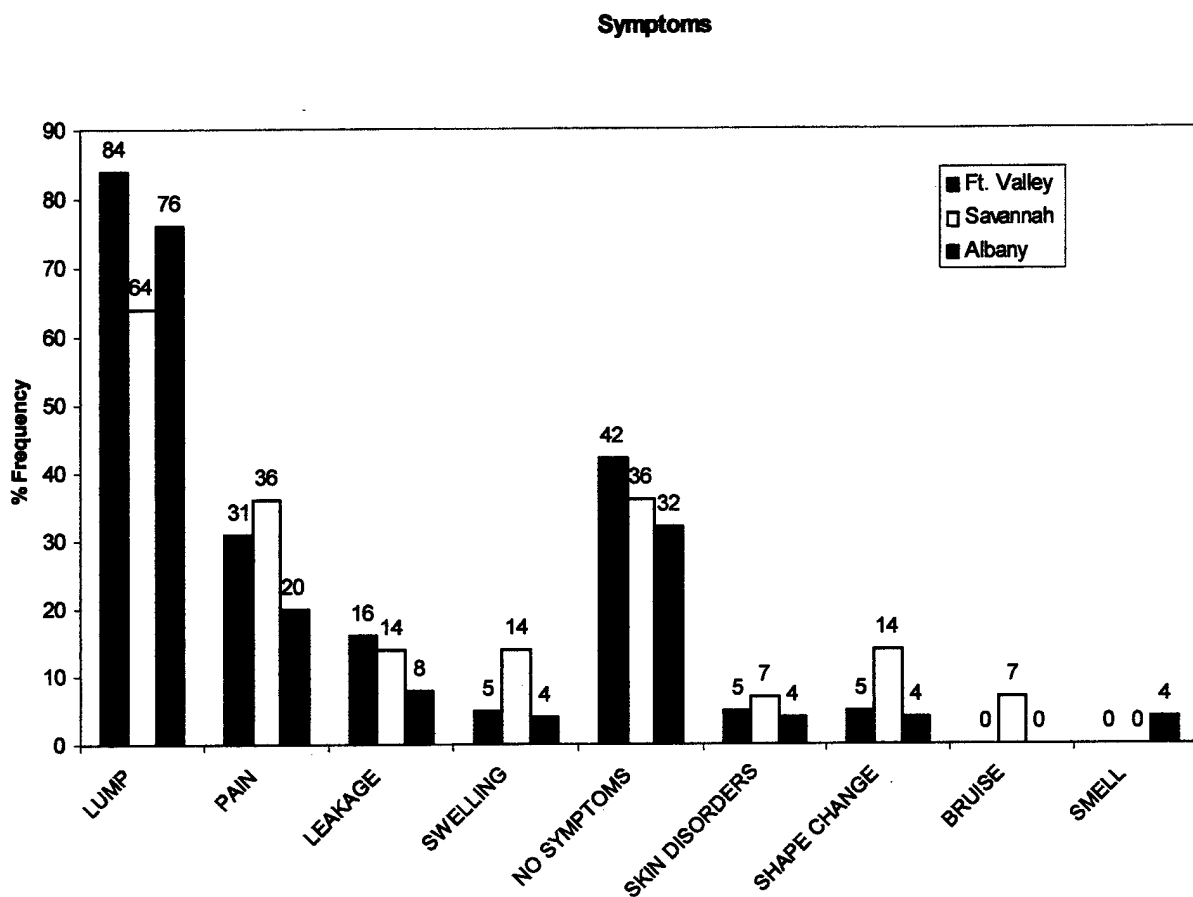
Treatment



Mamm = (mamogram), Faith = (faith, prayer, faith healing, scripture), Biopsy, BSE = (breast self exam), Mastectomy = (mastectomy, removal), Radiation = (radiation), Chemo = (chemotherapy), Bone Marrow Transplant, Surgery = (lumpectomy, removal), Positive attitude, Medication = (tamoxifen), Home remedies = (garlic, vinegar, honey, shark cartilage, nuts, pine bark, tofu, soy, roots, onion, tomato, wheat flour, grape juice, grapes, teas, tonics, cantaloupe, fruits, vegetables, aloe, oils, laetril, herbs, marijuana, vitamins)

Figure 3: Explanatory Model for Breast Cancer Treatment

Explanatory Models for Breast Cancer Symptoms



Lump = (lump, knot, mass, tumor, bump, lump under arm), Shape change = (hardening, heaviness, thickening), Pain = (pain, soreness), Smell, Leakage = (leakage, blood, spotting, discharge), Bruise, Swelling = (swelling, gland, size change), No symptoms = (no symptoms, no pain symptoms), Skin disorders = (rash, skin color, welts, itching, black spots)

Figure 4:

- Regarding respondents perception of causes for breast cancer, heredity, lifestyle and diet were top responses for all three sites, except the Savannah site differed in they causal beliefs about tobacco, violence, and faith. Violence (defined as being hit or sucking by men, injuring themselves by falls) was cited only four percent of the time by the other sites, but was cited twenty-six percent of the time by the Savannah respondents (see Figure 5).
- Regarding biomedical breast cancer knowledge, when asked how they described breast cancer before their diagnosis, silence or not being able to describe it is the most common response across the sites (see Figure 6).
- Most women in the survey reported visiting a doctor immediately upon experiencing symptoms of breast cancer. However, twenty-six percent waited over a month to visit a doctor and seven percent over a year. Reasons for delay included waiting for the lump to go away, not wanting to know if it was cancer, having a prior history of benign cyst, and experiencing difficulty scheduling an appointment with a doctor. These delays were seen primarily in the Fort Valley and Savannah sites (see Figure 7).
- Regarding social support, seventy-five percent of all respondents consulted a family member (child, parent, sibling, husband) about symptoms and diagnosis. Of this group, fifty percent talked first to their husbands.
- Thirteen questions were asked in an agree - disagree format about religious beliefs and church support (Table 3). In addition to these, questions about how faith helps women to understand their diagnosis of breast cancer were also asked in the ethnographic interview. For all sites, five beliefs indicated strong across site agreements:

1. God works through the doctors and nurse to cure cancer;
2. You would trust more in God to cure your cancer than medical treatment;
3. It would be your responsibility to pray everyday that God would cure you;
4. The strength of you own faith in God would determine if you cancer was cured; and,
5. You would want your church members to come to the hospital to pray with you.

Differing from the other sites, the Savannah site, regarding not asking people to pray for them in church (public forum), One hundred percent indicated that they would not ask people in church to pray for them. See figure 8 Agreement on religious beliefs.

Causes

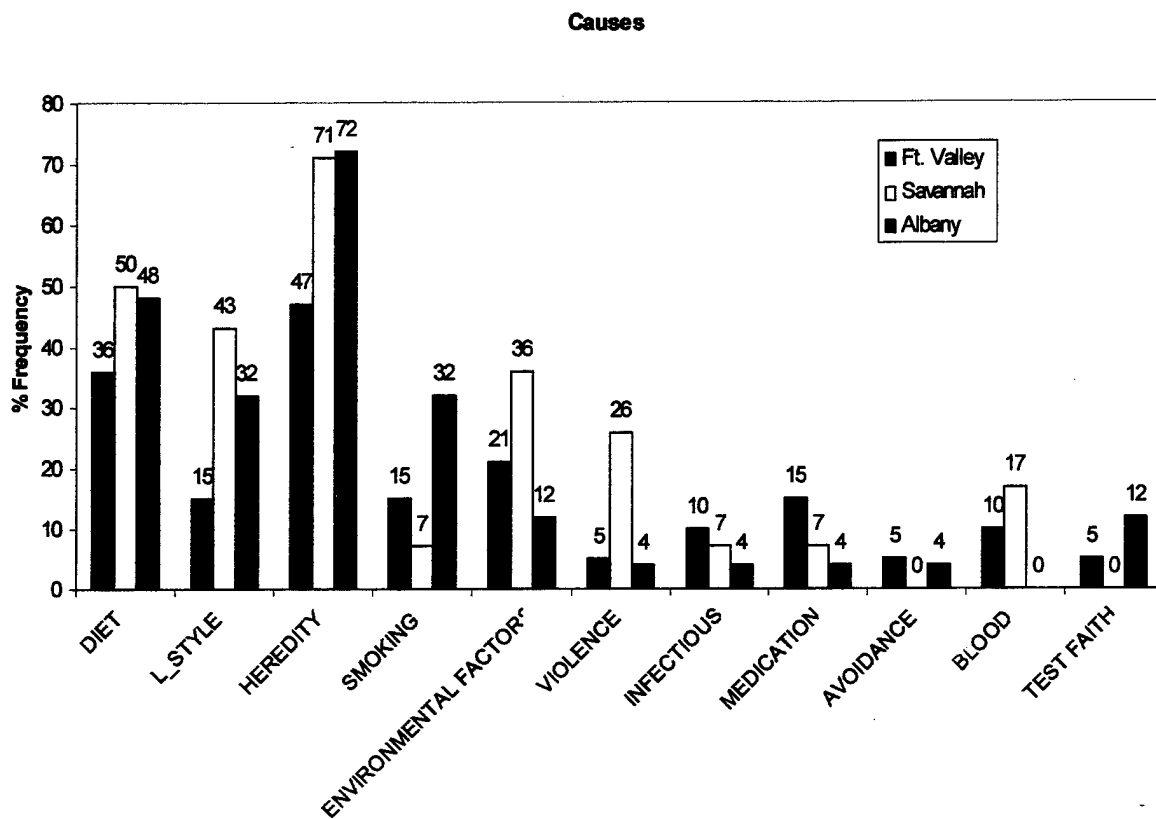


Figure 5: Explanatory Model for Causes of Breast Cancer

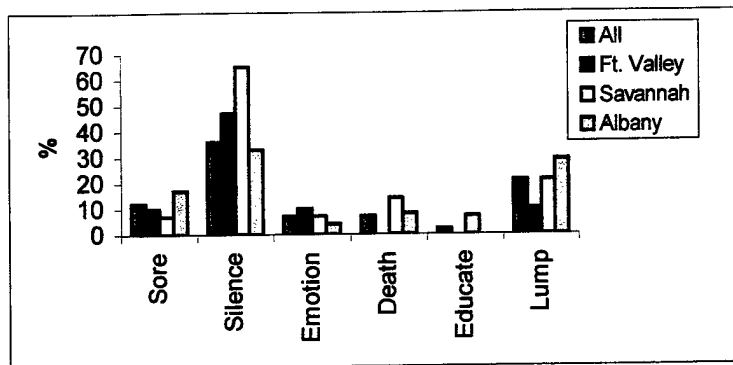


Figure 6: Breast Cancer Before Diagnosis

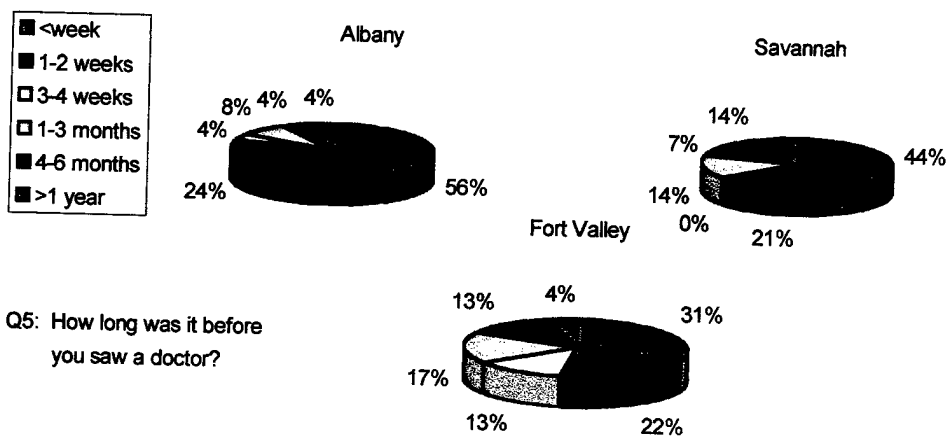


Figure 7: Delay in Seeing a Doctor by Site

- In order to discover the samples sources of information about breast cancer, of the information presented, the TV, books, pamphlets, newspapers, magazines and doctors were the most often chosen. Of these the doctor was the most trusted. See Figure 8 and 10.

Table 3: Agreement of Religious Beliefs

		Agree
1	God would work through the doctors and nurse to cure cancer.	91%
2	You would trust more in God to cure your cancer than medical treatment.	64%
3	You would refuse medical treatment and trust only in God to cure cancer.	2%
4	Only a religious miracle treatment could cure your cancer, not medical treatment.	16%
5	Your cancer would be because you had sinned against God.	2%
6	It would be your responsibility to pray every day that God would cure your cancer.	78%
7	The strength of your own faith in God would determine if your cancer was cured.	71%
8	Your prayer alone would do nothing to cure your cancer.	24%
9	You would want your church members to come to the hospital to pray with you.	72%
10	Your church members praying in church would help to cure your cancer.	64%
11	There would be a special ceremony for you in your church to cure your cancer.	17%
12	You would not tell anyone in your church about your cancer.	9%
13	You would not ask people in church to pray for you.	29%

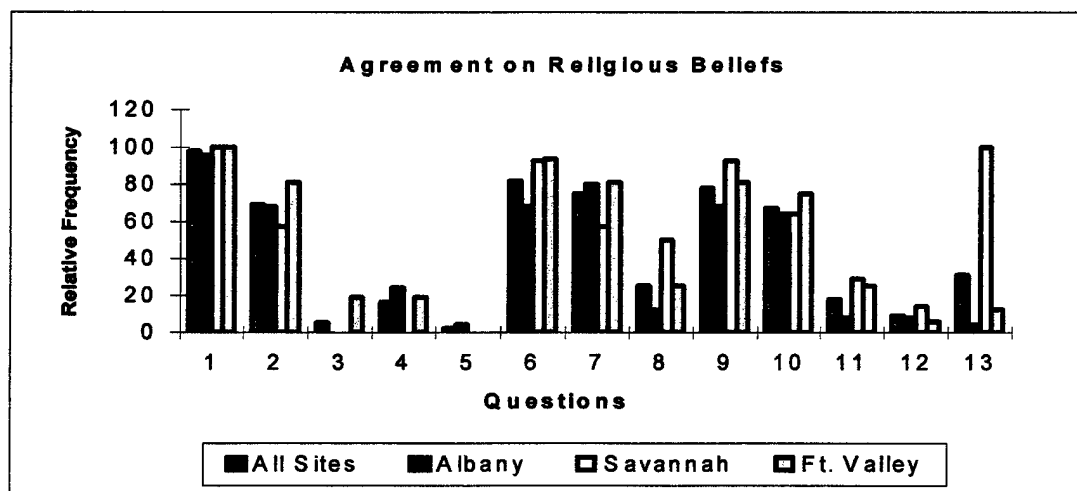


Figure 8: Religious Beliefs by Site

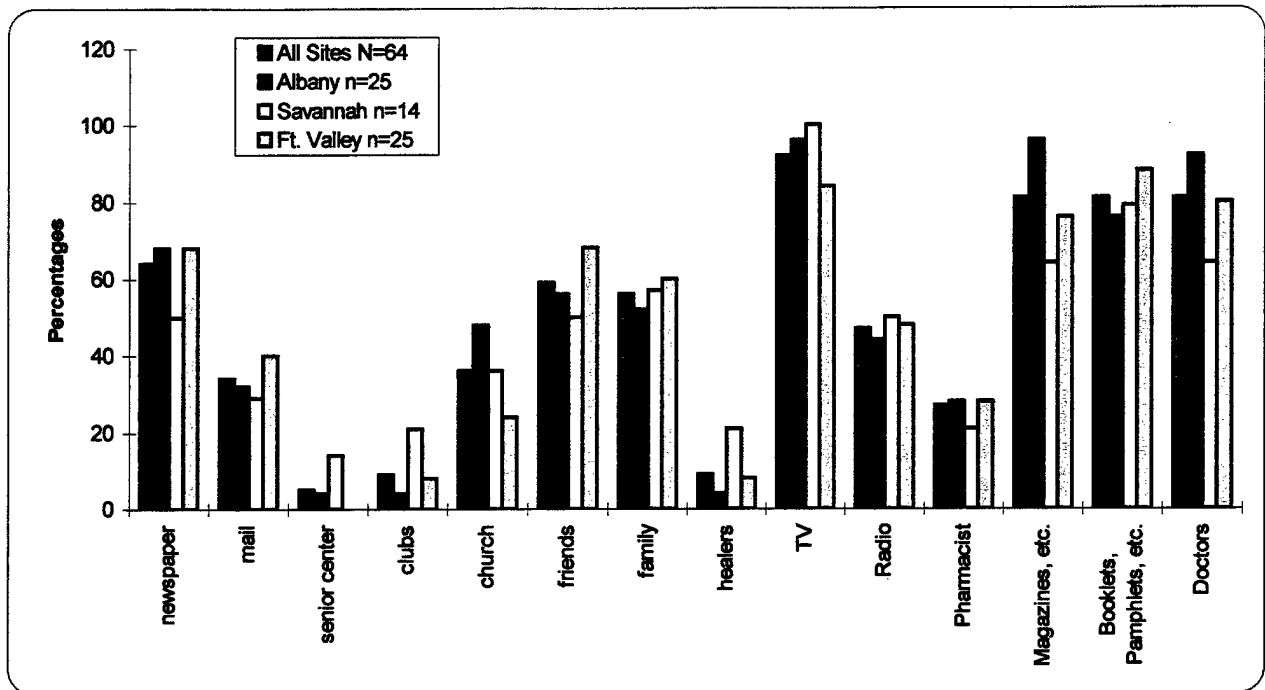


Figure 9: Sources of Information

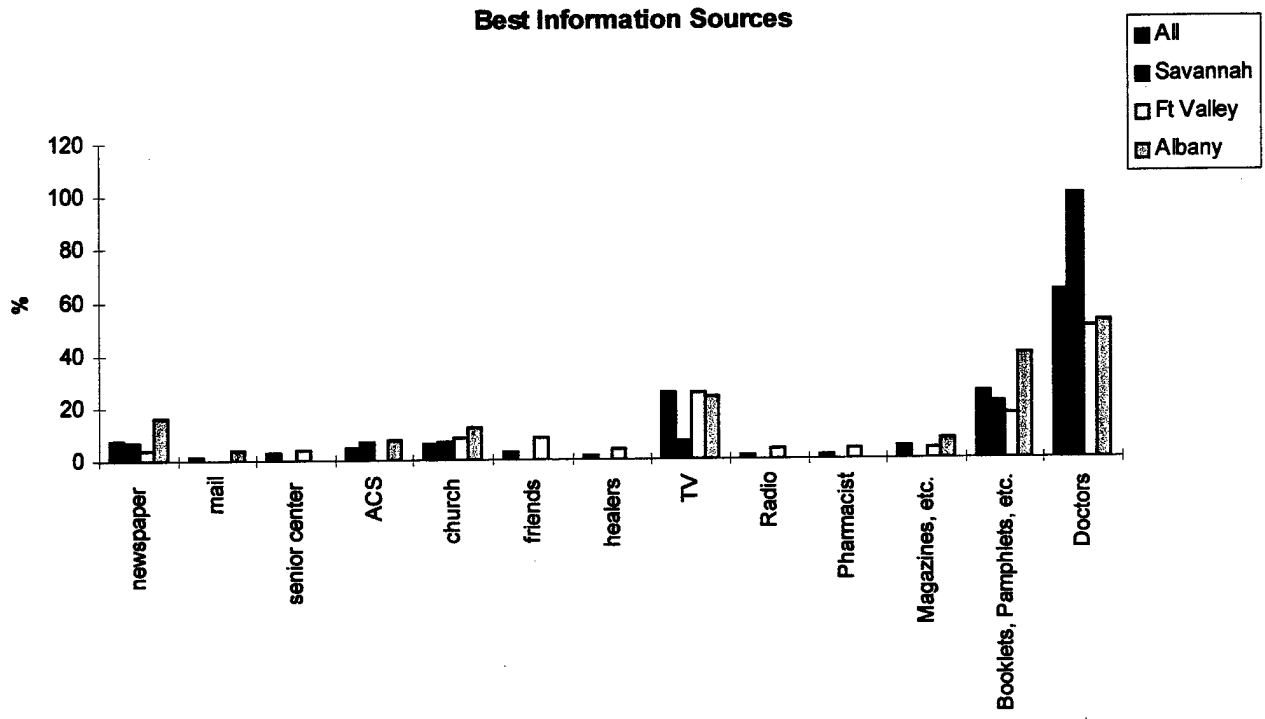


Figure 10: The Most Trusted Sources of Information by Site

Summary of Interpretation of Ethnographic Findings

The findings of the ethnographic research indicate that rural African-American women diagnosed with breast cancer have developed a belief system which integrates traditional beliefs with those of biomedicine. These women have incorporated their terms and concepts they learned in treatment into their beliefs about cancer.

The most significant finding indicates that breast cancer beliefs strongly influence the use of medical care. Diagnosis of breast cancer is the most salient factor for predicting preventive behavior; it is the driving force toward positive shifts in beliefs about breast cancer. Before diagnosis, a majority of women in all research sites were "silent" about breast cancer in their cultural knowledge and behavior. Over 90% did not think about the disease or think they would get the disease. Over 65% did not discuss cancer with anyone. Most did not utilize any preventive resources. Almost 50% believed they had "no symptoms" meaning that they did not recognize symptoms before diagnosis. Some indicated that they did not seek help after they discovered that had a lump. A majority of the women discovered their breast cancer during a visit to the doctor for another reason.

At the point of diagnosis and subsequent medical treatment, their beliefs begin to change integrating more medical terminology that describe breast cancer. Cultural domain and explanatory modeling analysis suggests that most of the women now use medical terms for their symptoms, causes, and treatment for breast cancer. The meaning of these terms, however, often do not correspond to those of medical personnel. Nonetheless, this medicalization process results in an increased use of preventive care and increased level of communication about the disease, particularly with their husbands and children. Results strongly indicated that the women were more empowered to take control of their health after diagnosis. Although a majority of women believe that cancer is inherited and/or the environment causes the disease, once they have made a shift in beliefs toward a medical model of cancer and preventive care, they become more empowered and feel more in control of their future. Changes in beliefs produced positive shifts toward preventive behavior. Thus, cultural beliefs regarding preventive care are certainly a stronger factor for predicting use than access or affordability of medical care.

The variation in beliefs among sites was significant in terms of the prevalence of traditional beliefs regarding causes and treatments for breast cancer and in terms of perceptions of the disease. The women who live in the more isolated site, Savannah, have stonger beliefs in the use of home remedies for treatment (albeit never as a replacement for medical care) and they are the only ones who talked about their believe in the importance of "blood" for causing the disease. Their cultural domain for breast cancer was smaller than the other sites indicating that their knowledge is more bounded about breast cancer. This indicates a lower level of participation in and communication with medical institutions and personnel. These findings suggest that they are less likely to seek care or even discuss breast cancer with their family and support networks.

Another significant finding points to the importance of religious beliefs in the experience and coping with breast cancer. 90% believe that faith helped them survivie the disease. All the

Another significant finding points to the importance of religious beliefs in the experience and coping with breast cancer. 90% believe that faith helped them survive the disease. All the women believe that God is working through the medical personnel. 64% believe that they would trust more in God to cure cancer than medical treatment indicating the importance of the integration of religion and medicine. 71% believe that their faith will determine if they are cured and 64% believe that church members praying will cure cancer. In large measure, religious beliefs are an influential force for the increased use of medical care, especially after diagnosis. It increases trust in doctors and the medical system. Once preventive care is included in their cultural beliefs, its use appears to be increased.

These findings indicate that promotional programs aimed at changing beliefs need to conceptualize these complex issues as a process involving changing beliefs before diagnosis of breast cancer. The positive changes reported in this study can be used as a model from which to work backwards. Promotional programs can certainly assume that positive changes can occur and that changes in beliefs before diagnosis will save lives by increasing rural African-American women's use of preventive care. They should also consider the variation of beliefs in more isolated populations.

MESSAGE DEVELOPMENT

Development of the educational message on breast cancer and its detection and prevention has already begin. Themes emerging from the findings of the ethnographic. Survey are being used to construct a model using the Witte's Persuasive Health Message (PHM) framework as a guide because it takes cognitive, affective, and sociocultural variables into consideration.

The PHM framework will provide the blueprint for the content of the message. Specific information components include basic information on breast health and breast disease, risk factors for low-income and minority women, the diet/nutrition/stress information, the importance of early detection, screening guidelines and resources, and referral information.

While thematic content forms the bedrock of the message, and influences whether or how the message is received and processed, diffusion strategies deal with how information is communicated through certain channels over time among members of a social system.

The Community-based Diffusion Model developed in collaboration with the National Heart, Lung and Blood Institute will be utilized. This approach bears a number of similarities with the Braithwaite-Lythcott Model for community organization for health promotion. The Community-based Diffusion Model recommends an understanding of the role, pattern of use, and the impact of the local, mainstream health care system such as private physicians, neighborhood clinics, hospital emergency rooms, and other health care resources. It is anticipated that in some communities, health care may be obtained through obscure venues such as herbalists and folk healers. *For members of a target community who continue to hold traditional health beliefs, it will be more effective to fit new health information into the old frame of reference rather than to dismiss traditional beliefs as ineffective or superstitious.*

ACCOMPLISHMENTS: Although the model is still in the development stage, a system of diffusion has to be identify and contracted to diffuse the education message. Home economist aides with the Fort Valley Cooperative Extension Service will be trained to deliver the breast cancer educational message. This community-based system has been in place for years and is a trusted resource of the targeted counties.

KEY RESEARCH ACCOMPLISHMENTS

- Successful completion of Phase I:
Ethnographic survey
- (Trained Lay Workers in the basic technique in exploratory research
- Development of breast cancer registry for African American women in rural, South Georgia

CONCLUSIONS

It is too early in the study to draw conclusions.

Appendix A

Georgia Department of Human Resources - Division of Public Health
Cancer Control Section - 2 Peachtree Street, NW - Atlanta, Georgia 30303-3142 - (404) 657-6600

Poverty Income Guidelines (200%) Breast/Breast and More

Effective July 1, 1997

Family	Monthly	Yearly
1	\$1,316.00	\$15,780.00
2	\$1,768.00	\$21,220.00
3	\$2,222.00	\$26,660.00
4	\$2,676.00	\$32,100.00
5	\$3,128.00	\$37,540.00
6	\$3,582.00	\$42,980.00
7	\$4,036.00	\$48,420.00
8	\$4,488.00	\$53,860.00

For family units with more than 8 members, add \$5,440 to the yearly amount for each additional family member.

BREAST HEALTH BELIEF SYSTEMS STUDY
Personal Information Questionnaire

Name (Last name, First Name): _____

Mailing Address: _____

Street Address (if different): _____

General Information

1. What is your age? _____

2. Do you have any children? ____ Yes ____ No

2a. If yes, how many? _____

3. How much schooling have you completed?

____ Less than 6 years ____ 7-9 years ____ 10 -12 years
____ 1-2 years of college ____ Completed college

4. Are you: ____ Single, never married ____ Married ____ Separated
 ____ Divorced ____ Widowed ____ Live with partner

If married, for how many years? _____

If you live with your partner, how many years? _____

5. Do you have any children? ____ No ____ Yes

If yes, how many? _____

6. Who lives with you now?

____ No one, I live alone.
____ Husband/male companion ____ Brother(s)
____ Mother/stepmother ____ Son(s)
____ Father/stepfather ____ Daughter(s)
____ Sister(s) ____ Other(s)

7. Including yourself, how many people live in your household? _____

8. How many years have you lived in this community? _____

9. Have you ever lived anywhere other than Georgia? _____ No _____ Yes

If yes, where did you live the longest?(City, State) _____
For how many years? _____

10. Do you attend church? _____ Yes _____ No

If yes, where do you go to church? _____

If yes, what church activities do you participate in?

_____ Choir _____ Prayer meetings _____ Prayer groups
_____ Support group _____ Sunday school _____ Other (Please describe) _____

11. At this time are you: _____ working for pay full time
_____ working for pay part-time
_____ self-employed
_____ not working for pay

12. Are you: _____ retired from paid employment
_____ laid off from a job temporarily
_____ unemployed with disability
_____ unemployed with out disability
_____ a homemaker
_____ Other(Describe) _____

13. What is/was your job called? _____

14. What is your yearly income? (Include your total family income from all sources and all the people that live with you.)

_____ Under \$10,000 _____ \$20,000 - \$30,000 _____ don't know
_____ between \$10,000 and \$20,000 _____ above \$30,000

15. Do you have a telephone? _____ Yes _____ No

If yes, What is the number? _____

If no, is there a number where you can be reached? _____

Health Care Information

16. Where do you regularly go for medical care?

- Private doctor A public clinic The emergency room
 Friends/neighbors Other No regular source of medical care

17. What do you use to pay for you medical expenses.(Check all that apply)

- Personal income Medicare The VA
 Family assistance Medicaid SSI
 Medical Insurance Don't Know
 Don't have any type of health insurance

18. If you have medical insurance how much do you pay? _____

19. When were you diagnosed with breast cancer? (year/month) _____

20. Who told you?

21. How many times have you been pregnant? _____

22. Do you still get your period? Yes No
If yes, do you use any kind of birth control methods?
If yes, what kind? _____

23. Do you drink alcohol beverages? Yes No

If yes, how often?
 1-2 drinks per week 3-4 drinks per week 5 or more per week

24. How often do you eat fried foods?

- 1-2 times a week 3-4 times per week 5 or more times per week
 once a month none

25. How many servings of fruit and vegetables do you eat each day?

- one two three four
 five six none other

26. How many servings of meat do you eat each day?

one two three four
 five six none other

27. How often do you exercise?

1-2 times per week 3-4 times per week 5-7 times per week
 once a month I don't exercise

28. Have you had a hysterectomy? Yes No

29. Do you take hormone pills? Yes No

30. Other than breast cancer, have you had any other kind of cancer? Yes No

If yes, what kind(s)? _____

31. Do you have any relatives who have had cancer? Yes No

If yes, who had cancer and what kind of cancer did they have?

We would like to schedule a time within the next few weeks when we can ask you additional questions about your experience with breast cancer. What days and times are you available?

Thank you very much for your assistance.

Causation:

6. What do you think causes people to get cancer?

7. What do you think caused your cancer?

8. Did you ever think you would get breast cancer? ___ Yes ___ No

8a. Why or why not?

9. Do you think that you did anything to cause your cancer? ___ Yes ___ No

9a. If so, what?

10. Why do you think some women get breast cancer and some women don't?

Treatment and Help Seeking Behavior

11. From the time you first suspected or learned something was wrong, what did you do to treat yourself first:

Second:

Third:

Fourth:

11a. How long was it until you saw a doctor about the breast problem?

(Probes: Do you feel you put off seeing a doctor or nurse; If you did not go to the doctor "promptly", why?; What made you decide to go to the doctor when you did?)

12. What did the doctor prescribe for your treatment of breast cancer?

(Probe: Did you have surgery, lumpectomy, mastectomy, chemotherapy, radiation?)

13. Have you completed this treatment? ___ Yes ___ No

(Probe: If no, why not.)

14. Prior to your diagnosis of breast cancer did you go to the doctor on a regular basis? ___ Yes ___ No

14a. Do you go to the doctor on a regular basis now? ___ Yes ___ No

(Probe for why or why not? If no, Probe for what things keep her from going to the doctor on a regular basis, and whether or not these things also keep her friends and family from going to the doctor.)

15. Had you had a mammography prior to your diagnosis of breast cancer? ___ Yes ___ No

15a. If yes, please describe the experience of the mammography.
(Probe for whether or not it was painful, etc.)

15b. If no, why not?
(Probe for whether or not a doctor ever suggested they have one, their ideas about mammography, whether they knew what a mammography was)

16. Did you have clinical breast exams before your diagnosis of breast cancer? ___ Yes ___ No
(Probe for why or why not. Probe for any attitudes, beliefs about the procedure, whether or not a health care provider ever gave them a breast exam, etc.)

17. Do you currently get mammographies and/or clinical breast exams as a part of your health care? ___ Yes ___ No
(Probe for why or why not. Do they now go to the doctor for regular exams? What are the reasons they do not currently seek preventative care and treatment for breast cancer? What are their constraints?)

18. Did you have a biopsy as a part of your exam to find out if you had breast cancer?

___ Yes ___ No

(If yes, probe for their experience of the biopsy. Did this effect their decision to continue or not continue treatment. Why? Probe for whether or not they know about the idea that air getting into cancer or cutting on a cancer can cause it to spread. Do they agree with that?)

19. Did you ever do self breast exams prior to your diagnosis of breast cancer? ___ Yes ___ No

19a. If yes, how often and how did you know how to do a breast self exam?

19b. If no, why not? *(Probe for rationale, emotions, ideas about touching the breast/body)*

20. Do you currently do breast self exams? ___ Yes ___ No

(Probe for why or why or not and refer to previous response in question 18)

21. Did you use any drug store medicines, vitamins, herbs, or special foods to treat yourself? ___ Yes ___ No

(Probes: If so, what did you use and why? If so, did you use these items before or after the doctor told you you had breast cancer? How did you decide what to treat yourself with?)

22. Has anyone (other than health care providers) ever given you advice about treating your cancer? ___ Yes ___ No

22a. If yes, who offered you advice and what did they tell you?

22b. Did you take their advice? ___ Yes ___ No
(Probe for why or why not.)

23. Does the church/your minister/God/ (choose most appropriate reference) help you to understand breast cancer and your experience. If so, how?

(Probe for details on religious beliefs and causation, treatment, symptoms and possibility of surviving breast cancer. Also, probe for how the church/minister/God offered support/advice. How does the church discuss health problems? Were there any prayer groups for you?)

Attitudes (towards health care providers)

24. Is your primary doctor ___male or ___female?

25. Is your doctor ___black, ___white or ___other (race/ethnicity)?

26. How do you feel about your doctor in general

(Probe for attitudes about other health care providers as well. How does she feel she's treated by health care professional including her doctor?)

27. What do you think most Black women prefer their physician be: *(Probe for reason for this preference)*

___black ___white ___male ___female ___doesn't matter.

Help Seeking Behavior(Formal and Informal)

28. Who did you talk to first when you personally discovered something was wrong with your breast?

28a. Why was this the first person you talked to?

28b. What did they tell you?

29. What responses did you receive from your family and friends about your problem.
(Probe for details on how people treated them, whether they were given advice or offered assistance)

30. What response did you receive from your minister?

31. Have you ever offered advice to others about breast cancer and what did you tell them?

32. If someone who has never heard of breast cancer asked you what is breast cancer what would you tell them?

33. Before your diagnosis of breast cancer, would you have described breast cancer in the same way that you just did? If not, how would you describe breast cancer then? (Probe for details symptoms, causes and treatment (mammography, etc.)).

34. What would you have done differently to prevent and treat your breast cancer?
(Probe for details)

35. Please indicate whether you receive information about breast cancer from the sources below. If, yes indicate how often.

	Yes	No	Often	Seldom	Never
a. Daily Newspaper					
b. Through the mail					
c. At senior centers					
d. At my club meetings					
e. At my church					
f. From close friends					
g. From family members					
h. People in the community with healing powers					
i. From t.v.					
j. From radio					
k. The pharmacist					
l. Grocery store magazines and other reading materials					
m. From health facilities					
n. From my doctors					

Of the information sources above, which ones do you trust the most?

36. What people/groups/organizations have helped you with breast cancer?(Probe for names, locations, and services offered.)

37. Do you feel that (choose only one):

a. You have a lot of influence over the things that happen to you? _____

OR

b. Do you believe that chance or luck plays an important role in your life? _____

38. For each statement below, please indicate whether these are similar to how you feel about your health.

	<u>Yes</u>	<u>No</u>
a. No matter what I do if I am going to get sick, I will get sick.	_____	_____
b. If I take care of myself, I can avoid illness.	_____	_____
c. Regarding my health, I can only do what my doctor tells me to do.	_____	_____

Free Listing

List all the symptoms of breast cancer that you know:

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

List all the causes of breast cancer that you know:

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

List all the treatments of breast cancer that you know:

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

ID# 47-7100

BREAST HEALTH BELIEF SYSTEMS STUDY Personal Information Questionnaire

Interview Date: 6-10-98

Interviewer: Mary Keaton

General Information

1. What is your age? 42

2. Do you have any children? Yes No

2a. If yes, how many? 4

3. How much schooling have you completed?

Less than 6 years 7-9 years 10-12 years
 1-2 years of college Completed college

4. Are you: Single, never married Married Separated
 Divorced Widowed Live with partner

4a. If married, for how many years? 14

4b. If you live with your partner, how many years? 0

5. Who lives with you now?

No one, I live alone.
 ~~Husband~~ male companion Brother(s)
 Mother/stepmother 1 Son(s)
 Father/stepfather 1 Daughter(s)
 Sister(s) Other(s)

6. Including yourself, how many people live in your household? 4

7. How many years have you lived in this community? Life

8. Have you ever lived anywhere other than Georgia? No Yes

8a. If yes, where did you live the longest?(City, State) _____

8b. For how many years? NA

ID# 47-7100

9. Do you attend church? Yes No

9a. If yes, where do you go to church? Christ Harvest Missionary Baptist Church
9b. If yes, what church activities do you participate in?

Choir Prayer meetings Prayer groups
 Support group Sunday school Other (Please describe) _____

10. At this time are you: working for pay full time
 working for pay part-time
 self-employed
 not working for pay

11. Are you: retired from paid employment
 laid off from a job temporarily
 unemployed with disability
 unemployed with out disability
 a homemaker
 Other(Describe) _____

12. What is/was your job called? Payroll Benefit Co-ordinator

13. What is your yearly income? (Include your total family income from all sources and all the people that live with you.)

Under \$10,000 \$20,000 - \$30,000 don't know
 between \$10,000 and \$20,000 above \$30,000

14. Do you have a telephone? Yes No

14a. If yes, What is the number? 883-7360

14b. If no, is there a number where you can be reached? NA

Health Care Information

15. Where do you regularly go for medical care?

Private doctor A public clinic The emergency room
 Friends/neighbors Other No regular source of medical care

ID# 47-7100

16. What do you use to pay for you medical expenses.(Check all that apply)

- Personal income
- Family assistance
- Medical Insurance
- Don't have any type of health insurance
- Medicare
- Medicaid
- Don't Know
- The VA
- SSI

17. If you have medical insurance how much do you pay? \$ 112.00

18. When were you diagnosed with breast cancer? (year/month) Nov. 1996

19. Who told you? Dr. Doug Calhoun

20. How many times have you been pregnant? 3

21. Do you still get your period? Yes No

21a. If yes, do you use any kind of birth control methods?

21b. If yes, what kind? NA Tubal ligation

22. Do you drink alcohol beverages? Yes No

22a. If yes, how often?

NA 1-2 drinks per week NA 3-4 drinks per week NA 5 or more per week

23. How often do you eat fried foods?

1-2 times a week 3-4 times per week 5 or more times per week

once a month none

24. How many servings of fruit and vegetables do you eat each day?

one two three four

five six none other

25. How many servings of meat do you eat each day?

one two three four

five six none other

26. How often do you exercise?

1-2 times per week 3-4 times per week 5-7 times per week

once a month I don't exercise

ID# 47-7100

27. Have you had a hysterectomy? Yes No

28. Do you take hormone pills? Yes No Tamoxifen

29. Other than breast cancer, have you had any other kind of cancer? Yes No

29a. If yes, what kind(s)? NA

30. Do you have any relatives who have had cancer? Yes No

30a. If yes, who had cancer and what kind of cancer did they have?

Thank you very much for your assistance.

ID# 477100

PROBES

**BREAST HEALTH BELIEF SYSTEMS STUDY
INTERVIEW SCHEDULE**

Best Available Copy

Interview Date: 6/22/98
Interviewer: [Signature]

INTRODUCTION:

This interview is part of a study on breast cancer among African American women being conducted by Morehouse School of Medicine. We are doing this study to learn more about the health care practices and beliefs of women in this county. I am going to ask you some questions about your experiences with breast cancer. If you do not understand a question, please ask me to repeat it. There are no right or wrong answers to these questions.

1. Tell me about your experiences with breast cancer.

I didn't have any symptoms that I knew of and it didn't showed up on the mammogram. I went back to the doctor and he said I had a lump.

Sequence of Events

I went to the doctor and he said I had a lump. I went to the doctor and he said I had a lump. I went to the doctor and he said I had a lump.

Symptoms

I had a lump in my breast. I went to the doctor and he said I had a lump. I went to the doctor and he said I had a lump.

Treatment

I had a lump in my breast. I went to the doctor and he said I had a lump. I went to the doctor and he said I had a lump.

Social Support

Family the whole thing. My mother and my sister. They were with me.

Use back of this page if needed.

ID# 477100

PROBES

2. How did you know something was wrong with your breast?

Skip if in narrative

Symptoms
Context

3. Who did you talk to first?

Skip if in narrative

My Dr. was the 1st person I talked to

Reasons for
choosing
person.

Details of
what they
talked about

That happens
usually and
on Monday

4. What did your family, friends and minister say and how did they act towards you?

My family was supportive, all the time
I was not at church and I am a member
of it. I did not see anyone there. I
was not at church and I am a member
of it. I did not see anyone there. I
was not at church and I am a member
of it. I did not see anyone there. I
was not at church and I am a member
of it. I did not see anyone there. I

Behavior

Stigma

Advice

5. How long was it until you saw a doctor?

- Less than a week _____
- 1 - 2 weeks _____
- ③ 4 weeks _____
- 1 - 3 months _____
- 4 - 6 months _____
- 7 - 9 months _____
- 10 - 12 months _____
- Over one year _____

5a. Why did you wait?

If over two weeks.

(See back)

6. Did you ever think you would get breast cancer? ___ Yes No

Explain.

I never really thought I would get it
I didn't think it could happen to me.

Why?

7. Why do you think some women get breast cancer and some women don't?

I have not done any research
Some people believe that it is not true
if that is true I have not done any research

ID# 47-7100

PROBES

8. What do you think caused your breast cancer?

I don't know I haven't really thought about it
if it has anything to do with the hormone thing - that would
be the best thing to know

9. What did the doctor prescribe for your treatment of breast cancer?

Nothing
nothing
nothing
nothing

10. Have you completed this treatment? Yes No
If no, why not?

nothing
nothing

11. Prior to your diagnosis of breast cancer did you go to the doctor on a regular basis?
 Yes No. Why or why not?

Skip if in narrative
I don't go to the doctor on a regular basis
but I do go to the doctor when I have a problem
with my health

12. Do you go to the doctor on a regular basis now? Yes No
Why or why not?

I try all of my appointments I know when to go to the doctor
and I try to go to the doctor on a regular basis
but I don't go to the doctor on a regular basis
because I don't have a problem with my health

13. What kind of doctor do you prefer?

White male doesn't matter
Black female other

14. How do you feel about your doctor(s) in general?

I like them they are very helpful with them
I have a good relationship with them

Detail both
good & bad
experiences

Oncologist - white male
General Practitioner - white male

Type of
doctor

nothing
nothing

Race

nothing
nothing

Gender

nothing
nothing

ID# 477100

PROBES

15. Did you have a mammography prior to your diagnosis of breast cancer?

Yes No

15a. If yes, when was the first one?

Tell me about these experiences?

5/96 they were normal they were not as painful as other women said they were. Believe

15b. If no, why not?

16. Did you ever do self breast exams prior to your diagnosis of breast cancer?

Yes No

16a. If yes, how often and how did you know how to do a breast self exam?

Once a month when I was in 6th grade we were taught how to do it. I was taught with my mother. I love getting better & I always remember to do it.

16b. If no, why not?

17. How did you feel about touching your breasts?

I felt okay.

18. Do you currently do breast self exams? Yes No

18a. If no, why?

19. Do you currently get mammographies as a part of your health care?

Yes No

20. Do you currently get clinical breast exams as a part of your health care?

Yes No

20a Do you think cancer is contagious? Yes No

21. Did you have a biopsy as a part of your exam to find out if you had breast cancer?

Yes No

Please describe your experience.

That's what we went home. ... I thought it'd be a ...

22. Have you heard about the idea that air getting into cancer or cutting on a cancer can cause it to spread? Yes No

22a. Do you agree with that idea? Yes No

Explain.

I have heard about ...

23. Do you think that high blood or low blood can cause cancer? Yes No

Explain.

I think ...

24. Tell me about any home remedies you've heard of for treating cancer.

I heard ...

- Drugstore
- Teas
- Roots
- Herbs

25. How does your faith help you to understand breast cancer and your experience?

I don't ...

- Beliefs
- Healing
- Surviving
- Minister
- Church Groups
- God
- Scripture
- Sermons

ID# 477100

33. What people/groups/organizations have helped you with breast cancer?

None

Names
Locations
Services offered

34. We are interested in finding out the ways you get information about breast cancer. I will read a list of information sources and ask you to tell me whether you receive information about breast cancer from the sources below before you had breast cancer.

	Yes	No
a. Daily Newspaper		✓
b. Through the mail		✓
c. At senior centers		✓
d. At my club meetings		✓
e. At my church		✓
f. From close friends		✓
g. From family members		✓
h. People in the community with healing powers		✓
i. From t.v.	✓	
j. From radio		✓
k. The pharmacist		✓
l. Grocery store magazines and other reading materials	✓	
m. From booklets, pamphlets		✓
n. From my doctors	✓	

I want to ask him why have I received my breast cancer. I want to know the difference between his practices and belief and what he need in me as a

35. Of the information sources above, which ones do you trust the most?

My Dr

ID# 477100

36. We are interested in asking you some specific questions about your faith. Please tell me if you agree or disagree with each statement:

	Agree	Disagree	Undecided
God would work through the doctors and nurse to cure cancer.	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You would trust more in God to cure your cancer than medical treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
You would refuse medical treatment and trust only in God to cure cancer.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Only a religious miracle treatment could cure your cancer, not medical treatment.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Your cancer would be because you had sinned against God.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
It would be your responsibility to pray every day that God would cure your cancer.	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The strength of your own faith in God would determine if your cancer was cured.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Your prayer alone would do nothing to cure your cancer.	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
You would want your church members to come to the hospital to pray with you. <i>Some of them come</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Your church members praying in church would help to cure your cancer.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
There would be a special ceremony for you in your church to cure your cancer.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
You would not tell anyone in your church about your cancer.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
You would not ask people in church to pray for you.	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

ID# 47-7100

FREE LISTING

The final questions in this interview are listing questions. I am going to ask you to list all the words or phrases that you can think of for the symptoms, causes and treatments of breast cancer:

First, list all the **symptoms** of breast cancer that you know:

<u>lump</u>		

Second, list all the **causes** of breast cancer that you know:

<u>hormones</u>		

Third, list all the **treatments** of breast cancer that you know:

<u>chemo</u>		
<u>Radiation</u>		
<u>herbal</u>		
<u>drugs</u>		

ID# 477100

SYMPTOMS

<u>Pile 1</u>	<u>Pile 2</u>	<u>Pile 3</u>	<u>Pile 4</u>	<u>Pile 5</u>	<u>Pile 6</u>	<u>Pile 7</u>
Lump in Breast	Swelling Leakage of Nipple Pain in Breast Sore Nipple Discharge Hypertrophy Erad Inflammation Lump in Breast Sore Nipple Redness of Nipple Sore Nipples Lump under arm Pain in Breast Pain in Breast Pain in Breast Pain in Breast					

REASONS

- Pile 1: That was the only thing I knew of at the time.
- Pile 2: I thought this was a late stage you would have a lump or diagnosed at a later stage.
- Pile 3:
- Pile 4:
- Pile 5:
- Pile 6:
- Pile 7:

ID# 477100

TREATMENTS

<u>Pile 1</u>	<u>Pile 2</u>	<u>Pile 3</u>	<u>Pile 4</u>	<u>Pile 5</u>	<u>Pile 6</u>	<u>Pile 7</u>
Rad. therapy Lumpectomy Chemotherapy PT	Rad. therapy Lumpectomy Chemotherapy PT					

REASONS

Pile 1: I had to go through some of these

Pile 2: I heard those some treatments

Pile 3:

Pile 4:

Pile 5:

Pile 6:

Pile 7:

ID# 47-2100

OBSERVATIONS

WE NEED YOU

to help us learn more about Breast Cancer.

The Morehouse School of Medicine is conducting a study on breast cancer among African American women. Part of the study involves talking with women who have been diagnosed with breast cancer. The interview will take a couple of hours and is **STRICTLY** confidential.

If you are 40 years of age or older, have or have had a diagnosis of breast cancer, and live in one of the following counties, we need your help to gather information which will be used in our health education program for counties located in South Georgia . We would like for you to participate in an interview. All information provided will be strictly confidential. Neither your name, social security number, or any other identifying information will be used to link you to the information you share.

Please help us help your sisters, daughters, friends, and neighbors prevent or survive breast cancer. Call the telephone number below for more information or to arrange an interview. All participants meeting the participant criteria will receive \$50 in cash.

NAME

PHONE

Working with Morehouse are faculty and staff at Fort Valley State University, Georgia State University, Savannah State University, and Albany State University.

Case #: 47-7100

**BREAST HEALTH BELIEF SYSTEMS STUDY
INTERVIEW SCHEDULE**

Interview Date: 5/22/98

Interviewer: _____

INTRODUCTION:

This interview is part of a study on breast cancer among African American women being conducted by Morehouse School of Medicine. We are doing this study to learn more about the health care practices and beliefs of women in this county. I am going to ask you some questions about your experiences with breast cancer. If you do not understand a question, please ask me to repeat it. There are no right or wrong answers to these questions.

Question: Tell me a little bit about your experience with breast cancer; you can start at the very beginning.

Answer: Um, when you say experience?

Question: When did you start to see any symptoms? or did you -- you can start with your mammogram when it first showed up.

Answer: Okay. I didn't receive, I didn't have any symptoms that I knew of or it didn't show up on the mammogram I found a lump in my left breast after having a biopsy done on my right breast. I went back to have a mammogram done on my left breast and nothing ever showed up on my mammogram. Um, I watched it for a couple of months, checking it call my general practioner, doctor to find out and he suggested that I consult with the doctor who had done that had done the biopsy on the my right breast. I did do that call him and he said up an appointment for me to come in. I did a needle biopsy but he explained to me in his office he took fluid and he sent that for testing and he said that if that showed up or abnormal then he would go in and actually do the biopsy too. biopsy the area and it showed abnormal he gave me a call and told me that I needed to come into the office and we scheduled when I was to have the biopsy done. I did that and after he did the biopsy was when he found out that it was breast cancer. and then a few days after that I had a mastectomy.

Question: Did you have any kind of social support

Answer: Social, outside of my family? My family because the whole thing in my opinion happened kind of fast and it was just like you know I found the lump got it checked found out that it was cancer, had the mastectomy stayed home a for healing. I had you know my people that I worked with come by and see me and stuff and then like my family was my biggest support. I didn't participate

in any of the um groups or anything to date. They encouraged me to participate in support like cancer support groups, and all that I didn't participate; just out of me not wanting to.

Question: Okay. What was the first person you talked to after you were diagnosed ?

Answer: My doctor was the first one I saw when I woke up from surgery. he told my surgeon , he was the one that told me that it was breast cancer and he gave me my options and at that time I was still, I was in the hospital for the biopsy done on outpatient basis. He stayed there at my bedside until I woke up from that surgery and he said um the results are not what we were hoping for and you know it is cancer and here are your options . At that point and time I told him you know what I want to have done, which was a mastectomy. He said okay we'll go I'll take it from there. After I left the recovery room and went back to the room um my husband and my father my sister all my family was there. I called people that I worked with to let them know that I was gonna be . See I had that surgery like on a Thursday and then the following Monday I had to turn right around and have the mastectomy done. So, I had to call them at work and let them know that you know what was going on so basically that's how that took place.

Question: What did your friends and your family and ministers say and how did they act towards you after you got home?

Answer: My family uh they were all there very supportive and all um, at the time I was diagnosed I didn't have, well I wouldn't say have, but I was not active in the church that I was a member of . Um, I was going and visiting other churches, so I did not tell a minister per say; the people that I worked with they were all there the ones that you know the ones that I worked closely with, they were there for me and didn't , as far as I could tell did not change.

Question: How was before you saw a doctor after?

Answer: 3 to four weeks

Question: If it didn't show up on the mammogram,

Answer: No, let me tell you what happen, I had my first mammogram in May, 2 years ago. When they did that mammogram something showed in my right breast. Okay, my doctor that had sent me to have the mammogram done, sent me to a surgeon. Now all this took place kind of fast, because I went to see him like on a Monday. He told me when I went to see him that I would hear something in the to 10 days as far as my results. That Wednesday happened to be field day for my son, so I was at the school field day. When I got home from field day, my

husband said you got appointment Friday at the doctor. You gotta have surgery, so he and my other doctor had set up my appoint with him , because the doctor had already gotten the results from the mammogram. On the right breast, the spot that showed up then, once Dr. Calhoun he got in and done the biopsy, it came back as cancer; calcium deposits or something he said. Okay, after that in September, in checking each month my breast myself, that the September I felt what I thought was lumps. So of course I went in and I asked my husband I said what he said to me was that may just be infected glands backed up mild ducts or something. So I said okay, so of course you know I had to check it everyday or then I started checking everyday at the point. So then I gave the you know If it don't go away in a week or two then I call Dr. Crimledge which is my general practioner. I called him and he said I can't tell anything by feel, so I'll just have you do a mammogram. He scheduled that and I went for it. The girl told me at that time when I went up she since, well there is a lump and you found it they may do an ultrasound but they didn't.

Question: So that was 2 weeks after you felt that lump. You went in 2 weeks ? You called your general doctor and he told you to go thru somebody and get a biopsy?

Answer: No okay say the ladder part in September. Probably as more like three weeks. I went to um have the mammogram done okay then when the results came back the mammogram they said nothing showed up and I went on from there. About probably about three more weeks some where along that time. I had my surgery and I'm saying that if that was like October. I actually had the um, mastectomy done the Monday before Thanksgiving of that year, so it happened from like September to the time I had the surgery and everything. I went to see him he withdrew the fluid and it came out that it was abnormal and I went in to see him; like all that happened within the week. That's why I say the three weeks you and the time I had it.

Question: Okay. Did you ever think you would ever get breast cancer?

Answer: No, I didn't

Question: Why not?

Answer: Well, I never really thought about it. And you know I guess just like anybody else you always somebody else and not me. I had hoped that I never would.

Question: Why do you think some women get breast cancer and some don't?

Answer: Well, from what I've told what I have been told um, um, it has a lot to do the types of things that you eat; all types of food that you eat; family history; see mine I'm the first to according to my mama and my daddy in our family to been

diagnosed with breast cancer, so. In reality I'm just been listening to a lot of things I've heard. Like a lot of people believe that they according to the area that you live in and you know all of this I don't know to be true because I haven't research it or anything; so I don't know.

Question: Did you ever believe that the area that you live in?

Answer: You know like I've seen then I say area um, I've seen like on t.v. on this 20/20 and DateLine where they have this um community of people and within that community like say if there are 40 women, 39 of them have it, that kind of thing.

Question: Okay. What do you think caused your breast cancer?

Answer: I don't know I haven't really thought about it, but if it has anything to do with me being white that would be the number one that I would say.

Question: What did your doctor prescribe for your treatment?

Answer: After the mastectomy or before? When I diagnosed, he said that you know I could do the mastectomy and the chemotherapy (6 months of that) the surgeon didn't say how may months but the cancer did.

Question: Have you completed the treatment?

Answer: Yes.

Question: Prior to your diagnosis of breast cancer, did you go to the doctor on a regular basis?

Answer: Not really. I just didn't want to. If they tell me to see him in a year, then I might have seen like 16 months later; 18 months later. That kind of thing. If I got sick I went but other than that no.

Question: Do go to the doctor on a regular basis now?

Answer: I try. All appointments I keep like my with oncologist when I finished chemotherapy I was supposed to go in and see him every three months and each time I've been in to see him he added so far a few times a month like when in and three months after I finished chemo, then he said you well come see me four months that kind of thing. I do keep those appointments and the only that I haven't is like to have papsmear that doctor says come to see me within a year, and my year was up for him last month. I have my papsmear done on June 12th so that kind of thing.

Question: What kind of doctor do you prefer?

Answer: It doesn't matter as long as they are good.

Question: How do feel about doctors ?

Answer: I like them, I'm happy with them.

Question: Do you have good or bad experiences?

Answer: Related to the doctors? No. I've been pleased them.

Question: Um, What do type of doctor do you have? Do you have an Oncologist?

Answer: Yes. Okay I have a general practioner, oncologist and a surgeon.

Question: Okay. Is your Oncologist, is he white or black?

Answer: White male. All of them are white males.

Question: And your first was mammogram was May 96'?

Answer: Yes.

Question: Can you tell me a little bit about your experiences with one breast? Were they painful?

Answer: I guess they were normal; they were not painful as other women had led me to believe. I didn't feel any great discomforts, or anything I didn't have problems with the exam itself.

Question: Did you ever do self breast exams prior to your diagnosis

Answer: Yes.

Question: How often did you do them?

Answer: Once a month.

Question: Um, who taught you how to do them?

Answer: Oh god, um, I guess when I was about the sixth grade we had a health nurse come out and show us and over the years I guess I got a little bit better you I feel something. I always questioned whether I was doing it wrong or not.

Question: How did you feel about touching your breast?

Answer: I feel okay.

Question: Do you currently give yourself breast exams.

Answer: Yes.

Question: Do you currently get mammogram as a part of your health care?

Answer: Yes.

Question: Do you currently get clinical breast exams as part of your health care?

Answer: No.

Question: Did you have a biopsy as part of your exam to find out if you had breast cancer?

Answer: Well the first was kind of weird because I had to go in and they um, put them wire in and put dye in so we would have things sticking out before the actual surgery itself um, but as far as like as how it felt I think the procedure itself went okay. I didn't any medical complications with the doctor told me about that I didn't. I didn't stay out work any longer than I should have with any kind of complications.

Question: Have you ever heard that air getting into cancer or cutting on cancer can cause it to spread?

Answer: Yeah.

Question: Do you believe that?

Answer: No.

Question: Why Not?

Answer: Well I my dad told me that were young girls he said several have had cancer and he said you they cut them and that made you die faster. That's about it. I haven't seem any type of studies

Question: Do you think high blood or low blood can cause cancer?

Answer: No. I hadn't thought about it.

Question: Do you want to explain why?

Answer: To be honest with you I haven't as much to what causes or whatever um like I said I always thought that it could never happen to me and then once I did get it. I felt it happened for a reason. I didn't try to research why. Why it happened or what caused it or what I did to cause it. I just except and go on. I don't think about well maybe high blood caused or it blood clots or this or that. I don't think about that.

Question: Tell me about any him remedies you've heard of for treating cancer(store bought drugs, herb teas..

Answer: I haven't heard of any

Question: How does your faith help you to understand breast cancer and your experience? Do you believe in healing and how you survived?

Answer: I just don't know how to explain it, But and I don't know if it's hard for you to understand, what happened with me is like I found the lumps and we did what we needed to do. I did have the mastectomy, I went through the chemo or whatever. I felt after that I felt that I'm okay so I don't dwell on the you know what If this happened or if they didn't get it all . I don't even think about it just like say you know the mastectomy was another like a another surgery that I had to get done. Like I said I've always felt that everything happens for a reason and it happened to me and then believing that God would talks care of me. I know that within itself has help . I mean if that's what you are talking, yeah I don't even think about I mean I think cancer when somebody else ask about it or if I feel there is a need to for me to share my experience with somebody, but you know other than that and other that saying oh I got to go to the doctor or something or if I got to take that pill or something that's as much as I think about. I don't dwell on it; why me or why did it happen to Me or anything like that

Question: What advice have you offered to others about breast cancer?

Answer: Well what I tell everybody that I talk to girls to say to make sure they do their exams that I cannot tell how the lump will feel, but just what I was always told that you will know. It will be different and you will know. Even the ladies I worked with they'll say I feel lumps anyway yeah I did too. bu that particular time I just felt like it was something else. And you I try to stress to them to get checked and to if they find anything or if they feel especially in my case if they feel like something isn't right then just don't stop with them saying it's nothing. You go on until you feel confident that you have done all you can, because if I had stopped when they did my mammogram and said nothing showed then who knows what might have happen. So that's basically what I try to tell them.

Question: If someone who has never heard of breast cancer ask you what is breast cancer what would you tell them?

Answer: Well I would probably tell them go down and look it up in an encyclopedia and go somewhere and find out if they don't know any thing about the disease itself because basically to be honest with you I cannot tell them medical terminology I know that both male and female can get breast cancer. I know that it can be deadly. I know the different treatments that can help, but other than that I can't tell them a whole lot of things. There are still some things that I heard after I 've gone through chemo and everything that I still don't know and that I'll ask questions something that I want to expand on I ask questions about well what is this and why is this but other than that you know I didn't do all this research like they said I had breast cancer they gave me a lot of stuff to read and movies and stuff to check out and I didn't even know that I after I had a mastectomy the hospital or somebody affiliated with the hospital would come by and see me and that I had tape that I was supposed to both read and help me deal better with having mastectomy and I didn't know that until months later. Like I was finishing with my chemo and I had the occasion that I was supposed to return it because I didn't want any of that stuff. Going through my stuff from the hospital the um thing that they give you with the breast fillings to use, that kind of thing I had just all kinds of stuff from the hospital and going through that, discarding some of that I found the tape at the bottom of the bag. I took it back to the place where I was supposed to turn it in and I told him I didn't know I didn't know that tape was in there and that was why I had kept it for so long. I didn't watch it and now if I hear something on t.v. on these talk shows when they come up and say well they think they found a cure for breast cancer or this person has breast cancer what happened I sit down and listen but as far as doing research like lady in the office was diagnosed with a different kind of cancer she was coming back to work when was going on of work I was doing chemo and she did radiation. She

was finishing her radiation when I was starting my chemo. When she was diagnosed she went and she got everything that she could read on her cancer. I didn't want to do that because you can read too much, so I didn't do that and the things I had questions about I asked my doctors and it went that way.

Question: What would have done differently to prevent and treat your breast cancer?

Answer: Nothing, because if it comes to know if the cancer if I got it from the way I eat, I still haven't change my eating habits. If they come said you are going are you die, if you don't quit eating those fried foods, I might consider but I got to weight it against me. I feel I got that one life and I want to be happy in living it and if that's the kind of food I eat I eat until I'm ready to change it. I did ask the doctor if he would ahead and take the other one off so I could have--he said no we can't do that for you.

Question: Do you think breast cancer is curable?

Answer: I believe it is

Question: I am going two questions and you tell which one you agree with:

Question: Do you have a lot of influence over the things that happen to you?

or

Do you believe that chance or luck plays an important role in your life?

Answer: I believe both. I believe that you do have influence over the things that happen to you and I also believe that you know

Question: Which do you believe the strongest?

Answer: You have the influence over what happens to you.

Question: For each statement below, please indicate whether these are similar to how you feel about your health.

Question: No matter what I do if I am going to get sick, I will get sick

Answer: How am I supposed to answer that?

Question: Yes or no, do you agree or disagree?

Answer: No. I don't agree with that.

Question: If I take care of myself, I can avoid illness.

Answer: Yes I agree with that.

Regarding my health, I can only do what my doctor tells me to do.

Answer: I disagree with that

Question: What people/ groups/ organizations have helped you with breast cancer?

Answer: None really. I wouldn't say help is like going to meetings and stuff like that?

Question: Just whatever services they provide.

Answer: Oh other than my doctors?

Question: We are interested in finding out the ways you get information about breast cancer. I will read a list of information sources and ask you to tell me whether you receive information about breast cancer form the sources below before you had breast cancer.

Daily newspaper:

Through the mail: No

At senior centers No.

At my club meetings No

At my church No

From family members No.

From close friend:

People in the community with healing powers:

From T.V.:

From radio:

The pharmacist:

Grocery store magazines and other reading materials:

From booklets, pamphlets:

From my doctors: because the other women in the office were getting their baseline mammogram before he had ever said anything to me about it and I would like when I would go in for papsmear would ask what he thought um why wasn't I and why were some of the people some of the women in the office getting one and it was just like his belief, his practice um the reason why he didn't tell me

like at 30 35 you can do it he thought at a later age you should have had the baseline and you know I would ask him that type of thing but that's as far as the discussion got about the breast cancer.

Question: Of the information sources above, which ones do you trust the most?

Answer: My doctor

Question: We are interested in asking you some specific questions about your faith. Please tell me if you agree or disagree with each statement.

Question: God would work through the doctors and nurse to cure cancer:

Answer: I think so I agree

Question: You would trust more in God to cure your cancer than medical treatment.

Answer: That kind of contradicting because if I believe that he would work through them by trust I have trust and faith

Question: Ask that again for me.

Question: Okay. You would trust more in God to cure your cancer than medical treatment?

Answer: Laugh. I don't agree with that not that , it's kind of contradicting. I do have trust in 'God but I trust that he allows me to receive the treatment through the doctors and nurses.

Question: You would refuse medical treatment and trust only in God to cure cancer?

Answer: No I would not refuse

Question: Only a religious miracle treatment could cure your cancer, not medical treatment.

Answer: No I don't believe that

Question: Your cancer would be because you had sinned against God?

Answer: No. I definitely don't believe that.

Question: It would be your responsibility to pray every day that God would cure your cancer?

Answer: My responsibility to pray? Yes I would think so.

Question: The strength of your own faith in God would determine if your cancer was cured?

Answer: No. I think other peoples prayer help too.

Question: Your prayer alone would do nothing to cure your cancer?

Answer: I agree with that

Question: You would want your church members to come to the hospital to pray with you?

Answer: Some of them can. My pastor usually comes by the house and we would have prayer.

Question: Your church members praying in church would help to cure your cancer?

Answer: I don't these trick questions, because I don't--let me explain this to you then I answer it this way. I don't believe that them praying at church alone cures the cancer I think we can pray that a cure be found ant that cure found in research through man and I think they are tools of God. That's what I believe so um they can pray that a cure be found and then I don't think that them praying will help cure it.

Question: There would be a special ceremony for you in your church to cure your cancer?

Answer: No. I don't think I would participate in it.

Question: You would not tell anyone in your church about your cancer?

Answer: That's not true.

Question: You would not ask people in church to pray for you?

Answer: That's not true, I don't agree with that.

The final question in this interview are listing question. I am going to list all the words or phrases that you can think of for the symptoms, causes and treatments of breast cancer:

First list all the symptoms of breast cancer that you know of:

Answer: lump, that's all

Question: What about causes?

Answer: Like I said I don't know as far as research and what has been proven but I had just heard that the types of food that you eat , and that's basically all.

Question: The third one is list all the treatments that you had?

Answer: Chemotherapy, radiation, mastectomy, radical and partial and that I have heard people other people that were unable to do chemo and radiation that

there were some drugs that they could take.

Question: First time you said lump in the breast and that's all you have.

Answer: I thought a lot of those were after you had been diagnosed, you would have some of those things or at a later stage

Question: First time you had not eating the right foods, smoking, caffeine, overweight, family history.

Answer: Because that's just what I heard?

Question: The next one--

Answer: For one I hadn't heard that it causes it.

Question: You said you didn't think or you had never heard of nothing

Answer: I have never heard that they caused it.