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13. ABSTRACT *(Maximum 200 words)*

Morehouse School of Medicine (MSM) conducts the Breast Health Belief Systems Study that seeks to accomplish three specific goals: (1) qualitatively analyze intracultural variations in knowledge, attitudes, and beliefs regarding breast disease among 75 low-SES, African American rural women who have received a diagnosis of breast cancer, (2) provide breast health information on an interpersonal level to a total of 600 demographically similar women (200 at each of 3 sites) who have not received a diagnosis of breast cancer, and (3) quantitatively test the effectiveness of an educational approach that utilizes an existing network of lay workers who are indigenous to the target communities. The study targets three different rural communities-an isolated area of extreme poverty, a poor rural area that provides access to a metropolitan center, and a poor rural coastal area that features a wide range of intracultural variations. The in-depth ethnographic analysis will form the basis for the development of breast health information that will be delivered by lay health workers. Georgia State, Savannah State, Fort Valley, and Albany State Universities are collaborators.

The research tests the hypothesis that a breast health promotion approach that proceeds from, and responds to specific belief systems among low-SES, African American, rural populations will motivate increases compliance to recommended cancer screening schedules, and positive shifts in knowledge and attitudes.

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Mary C Williams 8/19/98

PI - Signature Date

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I. INTRODUCTION

A. Purpose

Morehouse School of Medicine (MSM) conducts the Breast Health Belief Systems Study that seeks to accomplish three specific goals: (1) qualitatively analyze intracultural variations in knowledge, attitudes, and beliefs regarding breast health among low-SES, African American rural women who have received a diagnosis of breast cancer: (2) provide breast health information on an interpersonal level to 600 demographically similar women who have not received a diagnosis of breast cancer, and (3) quantitatively test the effectiveness of an educational approach that utilizes the USDA Cooperative Extension Service and an existing network of lay workers who are indigenous to the target communities. The study targets three different rural communities-an isolated area of extreme poverty, a poor rural area that provides access to a metropolitan center, and a poor rural coastal area that features a wide range of intracultural variations. The in-depth ethnographic analysis will form the basis for the development of breast health information that will be delivered by lay health workers indigenous to the target areas.

This study is being conducted collaboratively between gerontological and health communication researchers at Morehouse School of Medicine, and a medical anthropologist at Georgia State University with particular expertise in cultural models that guide health behavior, and in evaluating the effectiveness of primary care policies in the rural Southeast. In addition, a faculty member from a historically black college and university (Fort Valley, Savanna State, and Albany State) in each of the 3 targeted areas is participating as site coordinator for the project. This brings the disciplines of social works, sociology and community organization unto the team. The interdisciplinary research team for the proposed study creates unique strengths that do not currently exist elsewhere. Further, the opportunity to work collaboratively enables us to combine established anthropological and communication theory with public health research practice to determine the most viable and effective breast health promotion approaches for low-SES, rural African American women.

Background

The higher morbidity and mortality of advanced breast cancer among African American women than among white women is well documented in the literature.[1,2,3,4] While the incidence of breast cancer is higher in white women overall, mortality rates from breast cancer are higher in African American women. This higher mortality rate is though to be due to late stage diagnosis, socioeconomic status and hormonal issues.[5,6]

A strong correlation has been established between low SES and breast disease. The rate of breast cancer survival has been found to be lower in low-SES populations of black women than in black women nationally, and that it was particularly low when compared to white women.[7,8,9]

The issue of poverty strongly influences health because poverty contributes to ill health and ill health contributes to poverty. Currently available data reveal that approximately 30% of all African Americans reside in the southeastern United States. Of this population, 33.6% of adults and 44.8% of children fall below the federal poverty level.[10] Furthermore, blacks are significantly more likely to reside in states with the least generous Medicaid programs which tend to be the Southern states.

Despite the documentation of the morbidity and mortality of breast cancer among black women, there is limited information published on effective interventions to increase breast cancer among black women, there is limited information published on effective interventions to increase breast cancer screening. It is likely that black and white women alike are regularly exposed to health-related messages through the media and the work of public agencies and non-profit organizations. Commonly used health education materials and approaches, however, may be inappropriate for some minority populations. 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. Culturally appropriate interventions that take into account the beliefs, and cultural/environmental variables and preferences of African American populations are the ideal.

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 multicultural 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.[11,12]

Cultural Appropriateness. For the purposes of this research, we defined culture 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. Cultural knowledge provides "local logic" by which people make sense of their world and solve their health problems by providing a bounded set of options that motive specific health seeking behavior. Finally, cultural knowledge and practices are both reproduced and transformed within specific social environments and are constrained by the economic and political context of a specific group. Given the complexities of everyday life, cultural knowledge and practices are constantly being generated, thus creating shifts in the knowledge that is used for guiding behavior responses to disease, or threat of disease.

Belief Systems. Krepts and Thornton define beliefs as the basic units of thought that establish a relationship between at last two entities. Cognitive beliefs assess the truthfulness or falsity 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.[13]

In addition to fundamental beliefs, values, and attitudes, Kreps and Thornton offer three other organizing principles that can affect meaningful health communication: world view, social organization, and socialization. World view deals with one's attitudes toward religion, the nature of humans, and of the universe. An individual's world view subtly influences beliefs, values, and attitudes toward other realities in the individual's life. In this regard, Jahn explains that from an Afrocentrist perspective, it is not possible to separate theology from medicine or vice versa without violating the entire world view.[14]

Institutions such as schools, churches, law enforcement, mass media, and the healthcare system indicate a level of social organization. Views regarding the variables of beliefs, values, attitudes, world views, and social organizations are also disseminated through stereotyping, ethnocentrism, and proselytizing. Ethnocentrism can be a serious problem in the healthcare setting when the provider is unaware or dismissive of the values and attitudes of members of minority groups. Proselytizing is an attempt to force a cultural paradigm on followers of another cultural tradition. In the case of health and medicine, many physicians seek to elicit patient compliance with a treatment recommendation rather than patient cooperation.

An understanding and respect for a target group's beliefs, values, attitudes, world views, social organizations, and socialization are important factors of cultural sensitivity in health messages. These factors personalize the message through enhanced significance, credence, and comprehension, and increase the likelihood of that the target audience will understand and accept the recommendations. For example, among African American groups, Asante observes that, following the African tradition, much communication is verbal, and characterized by a strong collective mentality where the group is more important that the individual. There is also a strong need for harmony or compatibility.[15]

Preliminary Studies/Experience. The investigators' previous activities are particularly relevant to this research. Activities in cancer prevention and control have targeted Georgia or Atlanta populations, and include: (1989) a controlled intervention study, "Avoidable Mortality Study: Cancer Screening Intervention among Black Women in Inner City Atlanta"; epidemiologic study of black/white difference in cancer patient survival experience at the Georgia Center for Cancer Statistics; (1995) colorectal cancer screening intervention in an inner city community; a controlled, mailed intervention to promote the practice of colorectal cancer screening; (1996) an education intervention to increase the awareness of older women in rural Georgia about breast and cervical cancer and to motivate them to participate in screening programs; (1991) a health promotion intervention to promote self-help practices to reduce risks for cancer, diabetes, and heart disease. "Health Promotion Project for Older Blacks in rural Georgia;" and an assessment of social-cultural barriers to health care among black, white, Asian-Pacific Island and Hispanics in Coastal Georgia.

Preliminary findings on breast cancer from these studies suggest that blacks do not participate in early detection for cancer, even in areas where tests are low costs or free. Only 30% of inner city and 20% of rural women were likely to receive regular screening for breast cancer, rural, particularly coastal, study subjects rely heavily on religious beliefs and folk medicine. Thirty-six percent of those surveyed did not feel the urgency to get mammograms or Pap smears on a regular basis. Educational interventions that utilized lay health workers to conduct in-home education to increase adherence among low-income, inner city and rural women demonstrated a significant impact in increasing rates of breast cancer screening. The success of these studies was useful in designing the strategies for this research. These results suggested the need for additional attention to the screening, knowledge, and access and beliefs and behaviors from intracultural perspectives among the black population.

C. Scope of Research

The goal of the Morehouse School of Medicine Breast Health Belief System Study is to reduce the incidence of breast cancer and promote breast health seeking behaviors among low-SES, medically underserved, African American, rural populations. Positioned within three, uniquely distinct communities in rural Georgia, this project will aims:

1. To qualitatively determine intracultural variations in the variety, scope and depth of belief systems regarding breast disease among low-SES, rural African American women who have received a diagnosis of breast cancer;

2. Using the ethnographic data gathered, to conduct a demonstration project involving delivery of breast health information based on the belief systems of low-SES, culturally diverse African American populations on an interpersonal level;

3. To create and train an ongoing network of breast health information providers among individuals who have already gained access to and credibility with the target rural communities.

Target Areas. This research targets 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 flow to urban areas. The 3 counties are: Randolph (pop. 8,023; 57% black of which 87% lives below poverty levels; 74% of black adults 25 and older have less than H.S. education; the nearest major medical facility is in another county, app. 50 miles away); Twigg (pop. 10,079; 46% black with 35% living below poverty; 72.2 of blacks have less than H.S. education; nearest major medical facility is 23 miles in adjacent county); Liberty (coastal county with population of 52,745 resulting from recent immigration of civilian and enlisted military employees to the area; 54.9% black population with 58.8 with incomes below poverty; large population of blacks strongly maintain distinct West African traditions through their speech and cultural practices.)

Hypothesis. A breast health promotion approach that proceeds from, and responds to specific belief systems among low-SES, African American, rural populations will motivate increased compliance to recommended cancer screening schedules, and positive shifts in knowledge and attitudes.

Qualitatively, this research hypothesizes the following findings:

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

From a quantitative perspective, the hypothesis incorporates the following sub-hypotheses:

- Knowledge of breast cancer risks and prevention among women aged 40-65 will increase by approximately 30%.
- At follow-up, the percentage of women aged 40-65 who has had a clinical breast examination within the past year will increase by at least 20%.
- At follow-up, the percentage of women aged 40-65 who has had a mammogram within the past year will increase by at least 20% and will be at least 50%.

II. STATEMENT OF WORK

A. Project Objectives:

The proposed work will be achieved by the following objectives/procedures:

Objective 1: Operationalize Ethnographic Assessment of Belief Systems Year 01

Tasks:

1.1 Recruit and train interviewers. (Research assistants) for the qualitative component of the study.
1.2 Recruit study subjects.
1.3 Conduct ethnographic assessment of belief systems
1.4 Analyze data

Objective 2: Develop breast health information messages based on ethnographic analysis of the beliefs by target population. Year 02

Tasks:

2.1 Using qualitative data, formulate an interpersonal educational message
2.2 Structure the message for diffusion

Objective 3: Develop and Implement the intervention delivery system. Year 02 and 03

Tasks:

3.1 Develop curriculum and conduct training workshop for lay health workers.
3.2 Develop primary/secondary support systems.
3.3 Recruit study sample.
3.4 Conduct Intervention
3.5 Tract productivity of lay health workers

Objective 4: Evaluate the impact of the comprehensive intervention or breast cancer screening knowledge, attitude, and practices by measuring these parameters at baseline, and following the intervention. Year 03

Year 01 project activities involved operationalizing the ethnographic assessment (Objective 1)

Cultural knowledge of belief structures of rural residents provide a schema for the storage of information about breast cancer and a logic for solving problems that arise from the disease. They are taken-for-granted models of the world that are widely shared by members of a group. They play an enormous role in people's understanding of the world and their behavior in it. Consequently, they motivate behavior and provide a directive force in daily life. However, cultural knowledge is not shared equally throughout a group, and members use diverse sources of their knowledge. For example, Mathews et. al. found that African American women in rural North Carolina draw on multiple sources of knowledge in order to come to terms with their breast cancer.[16] Delineating variations in beliefs is an important design element to more effective intervention strategies.

Belief systems and their variations of the three populations will be qualitatively analyzed by using a set of data collection and analysis techniques grounded in symbolic and cognitive anthropology that assumes that people's behavior is guided by their interpretations of, and beliefs about breast cancer. Illness explanatory models (EMs) of an individual or group effectively determine the etiology, symptomatology, treatment options and use of health care providers. Beliefs are located in people's local worlds. They provide a person having breast cancer with a causal explanation for the disease. They also mediate the recognition and interpretation of symptoms. Local experiences mediate the number and types of options people receive as feasible for treating their disease. Once these have been determined, an action system (help-seeking behavior) is activated. EMs links beliefs and behavior within the context of people's experience. The explanations of breast cancer will be collected in narrative form with EM's constructed for each of the three groups under study. Each narrative will contain the following variables: 1) causes of breast cancer; 2) symptoms of breast cancer; 3) alternative treatment for breast cancer; 4) definitions of breast cancer; 5) expected treatment outcomes for breast cancer; and 6) attitudes toward breast cancer providers.

Decision modeling will focus on discovering and testing individual's criteria for making treatment choices. Shared standards for decision making about health behavior will be used to construct a model that will predict the different treatment options that people can be expected to choose. People's knowledge structures and conceptions of illnesses are inextricably related to their illness responses, and, consequently, to their decision making processes about treatment alternatives. The specific data that will be systematically collected to construct decision models that include the following variables: 1) constraints of decisions about breast cancer treatment choice; 2) intuitive rules for making decisions; 3) rationale for making choices, and 4) sequence of choices of treatment.

B. Tasks:

Organize Research Team
Recruitment of research assistants (interviewers)
Review of Surveillance, Epidemiology, and End Result (SEER) Program data
Recruit lay health workers
Using SEER data and lay health workers as liaisons, identify and recruit study participants
Development of question schedules
Research assistant (interviewer) training
Interviewing/data gathering
Data coding and analysis

III. EXPERIMENTAL METHODS, RESULTS AND DISCUSSION

1. Research Team/Management

This project is a multidisciplinary collaboration between institutions of higher education, community organizations, state agencies, cancer support groups, and public and private health care institutions.

Dr. Mary Williams, Principal Investigator, a medical practitioner and faculty member of Morehouse School of Medicine in Atlanta provides oversight for the study and will direct the project intervention in Year Three. John Smith, MSW, the Program Coordinator assists with the supervision of day-to-day activities including the recruitment of study participants. Larry Brown, Co-investigator with a MA in communications, will take the lead in developing the intervention message in Year 02. Through a subcontractual agreement with Georgia State University, Dr. Carole Hill, co-investigator and an anthropologist, took the lead in conducting the ethnographic assessment. Dr. Holly Matthews, of East Carolina University, who had conducted a similar assessment, consulted with Dr. Hill in the development of the research instruments.

The target population of this study is African American women in three rural sites in South Georgia, about 150 miles from Atlanta. In order to facilitate the implementation of this study, three historically black colleges and universities are involved in this project. A faculty member at Albany State (Southwest), Fort Valley State (middle) and Savannah State (southeast) Universities function as site Coordinators. These persons are Dr. Eugene Sherman, a sociologist and ordained minister, Clarence Williams a program leader for Cooperative Extension, and Ella Sims a social worker and herbalist. Unique to this research team is the staff of the Cooperative Extension Service at Fort Valley State University. Though agriculturally focused, this program conducts health education in its 13 county service area. Much of its community outreach is accomplished through collaborative efforts with community-based agencies and individuals indigenous to the areas. Six key females from these areas are key members of our team and function as Lay Health Workers.

Researchers have reported the existence of a lay communication system in geographic and culturally defined communities.[17,18] Using person indigenous to this system has worked well in health education projects requiring recruitment of such communities' members as project participants. Two to four persons, indigenous to the target counties and whom key community leaders recommended, were recruited as Lay Workers.

Team Management Problems: Most of the team management problems centered around long-distance supervision of field work. Although there were site coordinators, the distance between team members was 50 to 350 miles. All team members had other job responsibilities not related to this project.

2. Recruitment of Research Assistants (Interviewers) and Training

Senior or graduate students from three HBCUs near the target communities were utilized as research assistants. This approach provided a number of advantages: cultural an geographic familiarity, interinstitutional collaboration, and cost effectiveness in terms of controlling per diem and travel expenses in connection with the ethnographic analysis.

Summary of Training Session:

Four student research assistants from the three research sites were trained in interviewing techniques and data collection methods:

The research assistants were instructed on how to establish rapport with a respondent, how to make entre into the homes of respondents, and how to probe for additional detail from respondents in an agreeable and non-obtrusive manner. Trainees were informed on how to make observations of the interview setting, climate and atmosphere, why observations are necessary, and where to record these observations in the interview instrument. Exercises were conducted with the interview materials to promote interviewer comfort, familiarity and confidence with the interview setting and materials. Each student research assistant conducted a mock interview with the Georgia State University training team. Georgia State University assistants role played different interview scenarios the research assistants might encounter. These scenarios included: a difficult respondent, a shy respondent, and a talkative respondent. The trainees were given feedback and suggestions to improve their interview skills based on the mock interview scenarios.

Trainees were instructed on how to perform free listing and pile sort tasks with especially designed free listing and pile sort instruments. Training for the free list and pile sort tasks involved two stages. The first required the students to act as respondents while the Georgia State University team administered the test for them. The second stage required the trainee's to administer the tests to the Georgia State University team. The purpose of this two step training was to facilitate the student's understanding of the intention of free listing and pile sorting to the research data collection process, and establish familiarity with the task materials.

In order to facilitate their understanding of the research process, the trainee's were informed about the goals of the ethnographic research phase of the study and the methods used. Students were encouraged to give an explanatory model analysis of the mock interviews an free list/pile sort tasks. This last exercise furthered their sensitivity to the study goals and the significance of their place in the research process. The final stage of the training involved familiarizing the trainee's in the data management software package, EZ Text. Students were shown a demonstration of the software and encouraged to become familiar with it by entering answers from the mock interviews onto the interview database.

Throughout the training, questions were encouraged and time allotted for discussion of all aspects of the materials covered. Training materials were presented in a folder for each student and included a Training Manual for future reference, Interview Schedule, tape recorder, batteries and tapes, free list and pile sort cards, a training agenda, EZ Text instructions, instructions on where to send completed interviews, and a floppy disk for copying transcribed interviews and the EZ Text database. They were instructed to send all research materials to the co-investigator at Georgia State University. They were asked to send the interviews after every five for review and data analysis. Mailing materials were provided for this purpose. The faculty (coordinators) at each research site was also informed of this procedure. Copies of the training manual were provided to all faculty at each research site. In addition, the lay health workers for each site received a packet of Personal Information Questionnaires.

Recruitment and Training Problems

Initially, the plan was to recruit two students from each school for a total of six. Two of the recruits did not show up for the training. Because of the intensity of the training, additional sessions for those two students were not practical, therefore they were eliminated from the study. An on—site session was planned with each student after each had completed five interviews to follow-up on the accuracy of their data collection activities and to allow the Co-investigator, Dr. Hill to get a feel for the target areas. A site visit to our Southwest site did not occur this period due to team management, program development, and subject recruitment delays discussed under other sections of this report.

3. Review of SEER Program Data

The Surveillance, Epidemiology, and End Result (SEER) Program is a national effort funded by the National Cancer Institute whereby states collect and maintain a database on cancer for their counties. The Georgia Center for Cancer Statistics is a part of the SEER program. Morehouse investigators had been told that breast cancer data existed for each county in Georgia. In the development stages of its project, Morehouse proposed to utilize this database to assist with the identification of African American breast cancer survivors in our target counties. Once identified, the diagnosing physicians would be contacted and assistance solicited to recruit their patients into our study. Upon receipt of our grant, a formal request was made to review this data. It was soon learned that breast cancer data for the three counties targeted were incomplete and not ready for review. Demographically similar counties where SEER Program Data was complete were selected. This increased our targeted counties from three to six. Approval to utilize the SEER database had to be obtained through the Human Research Review Board of the Georgia Department of Human Resources, Office of Regulatory Services. The Board's review of our request resulted in the two separate request for additional information about the project and since this Board does not meet monthly the approval process extended over a five-month period.

4. Identification of Study Subjects

In Project Year 01, seventy-five African American women with a current or past diagnosis of breast cancer were to be recruited to participate in our ethnographic survey. Because of the delays created by lack of complete SEER data in target counties and the lengthy approval process, the research team developed the following alternative strategies to identifying potential study subjects.

a. Formed Partnerships with agencies/organizations in the state focusing on breast cancer screening/early diagnosis. These organizations are:

Georgia Chapter of the Black Nurses Association

BreasTest and More Programs, Public Health Division, Georgia Department of Human Resources, funded by the National Cancer Institute.

b. Cancer Treatment Centers. Oncology Centers in South Georgia were identified, contacted about our study and asked for assistance in identifying and recruiting study subjects.

c. Private Physicians in our targeted counties were contacted about the study and asked for assistance. The Georgia State Medical Association, comprised of approximately 900 minority physicians allowed us to use their membership directory to identify and contact physicians in our target areas.

d. Public Health Departments in very rural areas are often the only nearby health facility. Directors at such facilities were also contacted for referrals.

e. Established an affiliation with a home healthcare service providers. An affiliation was established with the Older American's Council of Middle Georgia, which has case workers in one urban, and six rural counties.

These strategies proved very successful. Sixty-eight percent of our referrals came from these sources. By June 30, 1998, 61 African American female subjects were enrolled in our study.

5. Recruitment of Lay Workers

Eight persons were recruited was Lay Workers from the criteria that they have at least a high school education, be natives of the target area and have a background of information dissemination through the formal and information communication systems, and be recommended by a key community leader. The role of these workers was to contact those breast cancer victims/survivors who had agreed to participate in the study, explain in detail the study, collect a demographic profile, and obtain a signed consent form from those qualifying for the study.

Lay Workers also participated in regular planning meeting with the Research Team. Their involvement in Project Year 01 expanded over a four-month period. They were compensated for their time and travel/telephone expenses with a $500 honorarium.

Lay Worker training was conducted in April and consisted of a four-hour session, which included detailed explanation of the research purpose and protocols, recruitment criteria, instrument review and procedures for handling data. The site coordinators (designated faculty person at each participating university) were responsible for supervision of the lay workers.

Problems. There were no problems in recruiting qualified and enthusiastic workers. Because of the delays in identifying study subjects, three of the eight lay workers dropped out of the project.

6. Recruitment of Study Participants

Twenty-five (25) subjects were to be chosen from each of the three target area using the following criteria: 1) low-SES (as defined by BreasTest and More, see Appendix B), 2) African American descent, 3) diagnosis of breast cancer, 4) over 40 years old, and 5) lived in rural Georgia for past 15 years. Targeted or purposive sampling was used for selecting subjects in each study site. Ethnographic research makes it possible to use smaller samples than quantitative data since the overall goal of qualitative research is depth, not breadth. This number is sufficient to approximate a representative sampling for the study population in each site and guarantees intracultural variation within the subsamples. Once identified, subjects were recruited to participate in this study utilizing the pre-existing lay outreach system.

Nonprobability samples yield a representative picture of salient features of the target population; a small number of informants provide representative pictures of aspects o cultural knowledge distributed within the population. We are attempting to minimize variation in knowledge for a single cluster of respondents in one site and while maximizing variation in knowledge among respondents at all sites. Respondents were selected from relatively homogeneous site-specific populations and from comparably heterogeneous populations across sites. Although this type of study does not use random sampling, it is selectively sampling specialized knowledge of the key variables set forth in the study.

Recruitment Problems. The major problem in recruiting study subjects was finding that the SEER Database, from which the study subject registry was to be developed, was not complete for the counties we had targeted. This required the use of the alternatives described above. Consequently, this caused a four-month delay. The turning point in subject identification and recruitment was our approach to the Georgia State Medical Association, which is composed of approximately 900 minority physicians, several are Morehouse graduates.

GSMA allowed the research team to use their physician directory to call, explain the project, and enlist assistance in identifying subjects for the study. A flyer and promotional brochure was developed and distributed to select GSMA physicians in the targeted area. Follow up calls were made. Calls from potential subjects and physicians alike came in response to the flyers. The most significant however, was the identification and recruitment of a breast cancer survivor who is a nurse in an oncology clinic and was actively involved in several support groups. Within a relatively short time (less than 45 days), of her involvement, she had identified, received consent and referred over 28 participants for the study.

7. Development of Question Schedules

a. Development of the Personal Information Questionnaire (See Appendix A)

The personal information questionnaire was designed to collect general demographic information and health behavior including information regarding the respondent's current health status, access to medical care, general reproductive health history, diet, alcohol consumption and exercise practices.

b. Development and Pre-test of the Interview Schedule (Appendix A)

The research instrument was developed in January and pretested in two sites adjacent to the proposed study sites during February and early March. The women were recruited for the pretest by the Lay Health Workers and were members of Breast Cancer Survival Support Groups.

The initial draft of the pre-test interview schedule was developed in consultation with Dr. Holly Matthews, East Carolina University. Pretesting allowed the research team to assess the pertinence and reliability of the interview questions and the time allotted for answering them. These assessment led to several revisions of the research instruments. In addition, during the pretest, exceptional rapport was established between the respondents and the researchers culminating in short focus groups at the Savannah and Macon sites. The focus group information enabled the research team to further refine the interview schedule.

Problems: Pretesting was designed to include subjects similar to those to be recruited for the study and to be conducted in each of the three sites. Because of initial outreach and scheduling difficulties of the site coordinator at Albany State University, pretesting was not done in our southwest site – the poorest of the three areas. This presented a major problem with evaluating our instruments since educational appropriateness was a major factor. As an alternative, five breast cancer survivors from an Atlanta Public housing complex were interviewed for pretesting purposes.

An unexpected issue was raised during the pretesting phase of the study. While having experienced breast cancer were the major qualifying criteria to participate in the study, it became clear that similar questions need to be asked of a sample of women who have not been diagnosed with breast cancer. Women with breast cancer have possibly been socialized into beliefs that they did not have before contracting the disease. Therefore, the participants in the pre-test and the lay health workers suggested that the study expand the sampling procedures in order to collect data from women who have not had breast cancer.

Table 1 summarizes the pretest demographics for participants.

Table 1: Summary of Pretest Demographics:

Sites	Number of Respondents	Average Age	Years in Community	Average Income
Savannah	5	58	24	18,000
Macon	6	55	19	27,500
Atlanta	4	63	30	12,000

The average age of the 15 pre-test respondents is 58 years. The average number of years since diagnosis of breast cancer for the 15 respondents is 6.26.

Following both the individual interviews and the focus group discussions the respondents were encouraged to provide their comments on the pre-test process. In particular, they were asked to assess the appropriateness and relevance of the questions, and the amount of time it took to complete the pre-test.

The research team also toured the towns and communities in the research site. The team met with the lay health workers to discuss sampling issues and recruitment of respondents. The issues covered at this meeting reviewed the handling of the data, methods of respondent enumeration and signing of consent forms.

Pretesting the study instruments provided valuable information, which was used in refining these instruments to make them more appropriate for the target population.

8. Interviewing/Data Gathering

Both quantitative and qualitative methods were used in collecting data to enable investigators to assess the assumptions about belief systems and responses to breast cancer.

The Personal Information Questionnaire consisted of structured questions designed to collect a general demographic profile of the respondent and information about her health behavior. The questionnaire also included items targeting locus of control – an important factor in how one makes decisions. The Lay Workers administered this questionnaire to subjects referred from the recruitment sources described earlier. The informed consent was obtained prior to administering this questionnaire. Confidentiality was addressed by the following:

- No names, social security numbers, addresses or other identifying information appears on written interview forms or audiotaped materials.

- An I.D. number was generated for each respondent by taking the FIPS code of the county of the respondent and four numbers selected by the respondent (last 4 numbers of social security, telephone, house number, etc.). This number was entered on the interview forms and audiotapes of the respondents. Consent forms and research assistants' interview logs (containing names and addresses for disbursement of incentives) were not attached to completed interview forms.

Several ethnographic techniques were used to collect data to assess the cultural knowledge (beliefs) about cancer including interviewing, free listing, and participant observations.

Research assistants administered an interview instrument, consisting of structured and semi-structured questions. The questions were designed to elicit descriptive information for determining the EMs and decision-making processes for breast health disorders. The interview instruments were pre-tested in a demographically similar community that was not proximate to the target areas. The respondents were asked about their beliefs about causes of breast disorders and related problems, why people have them, what they think about people who have them (attitudes), about symptoms (early recognition), what they did when a breast disorder event occurred (use of formal and informal systems), and how these disorders have affected their lives (impact on family, friends, community and work). In the interview, although the respondents were given latitude to choose her own order and manner of presentation, there was a systematic attempt on the part of the interviewer to completely cover the topic under analysis. These questions should yield in-depth information about rural residents' knowledge and experiences of breast disorders. Interviews were also audiotaped to ensure an accurate representation of subjects' responses.

Another technique that was used is free listing. Respondents for each subsample were asked to list the types of breast health disorders they know about and the treatments for each type of disorder. Free listing is a technique that allows researchers to explore the cultural limits of an area of knowledge, belief, or behavior.

Participant observation was used, and is defined as those modalities that attend to interaction, context or situation and to narrative or case studies. By interaction, we mean that the participant-observer will reside in or near the target communities under study. An important aspect of this participation is interaction with residents in multiple contexts. Experience suggests that in multiple, ad hoc contexts, informants offer further insights on their cultural models and world-views that will directly inform the ethnographic modeling instruments that will be emerge. An major criterion for selection of the research assistants was be that they live in or near one of the target communities. They would involve themselves in local events, such as church functions and community events. They would take detailed notes of all observations and informal interviews. When possible, observations will be made in households and other private gatherings.

Observational fieldnotes consisted of two categories; (1) general observations, and (2) structured observations that are directly related to breast health and breast disorders.

Fieldnotes were recorded to assure confidentiality. No names were used in the notes and the researchers will explain the anonymity of all participants. Researchers were given explicit instructions on the systematic collection and management of fieldnotes.

Problems:

The major problem with conducting interviews and data collecting was delays encountered in identifying study subjects. The four-month delay created havoc for the study schedule. It was anticipated that all interviews would have been completed by the end of May. This was not accomplished. In addition to subject identification, recruitment and interviewing problems were encountered:

Several subjects on the registry had problems with disclosure – they did not want to talk about their cancer. This created some frustration for lay workers since they made the initial contact to start the interview process.

Women from higher SES were more willing to participate in the study, but did not meet study's income criteria. Also, women from higher income levels were more likely to participate in support groups.

The four month delay put the start of the interview process into April and May. Most of our student research assistants were graduating seniors. Two of our three site coordinators were teaching faculty. April and May were busy months from academic events that took priority over the study schedule. Communications problems developed between investigators and site coordinators surrounding scheduling and deadline issues.

Subsequent to these problems, data collection continued into August.

9. Data Coding and Analysis

Data Coding and Analysis begin in July and is therefore incomplete. Data management and analysis proceeds 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 catchment area; (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 intracultural concordance and variation. Fieldnotes are treated as texts, and transcribed and coded.

IV. EVALUATION

Quarterly evaluations on the process of implementing the project were conducted. This enabled to continual review the progress and to make changes as needed. An end of the year evaluation was conducted by an outside person, Wilbur Watson, Ph.D. Dr. Watson is Professor of Sociology at Morehouse College and well known for his scholarly work in folk medicine, aging and social behavior among African Americans. Below is a summary of his review and recommendations.

To operationalize the ethnographic assessment of belief systems. This effort was begun, but not consummated during the first year of the project.

Designs of the instruments were completed, along with the training of four research of four research assistants in the uses of those techniques. However, based upon the report submitted by Carol Hill, Co-Investigator, data was slow coming from the research assistants or faculty coordinators. Since these data are important to the design of the messages for the interventions, the problems related to the collection of field data needed to be resolved promptly. It appears that successful efforts have begun to resolve the problem of data collection.

Interviewers (research assistants) will be recruited and trained in the procedures for the collection of qualitative data for this study. These activities were successfully executed in April, 1998.

Analyze the data. This task has not been realized. The Co-Investigator, Professor Carole Hill, was unable to complete this task because of difficulties in data collection and making contact with Faculty Advisors and Research Assistants. Consequently, by the time of this report, the data analysis process had just begun on a significant scale.

A Methodological Note.

The planned techniques for data collection were detailed and comprehensive, especially the questions designed to guide the collection of qualitative and ethnographic data. There was not, however, an explicit plan for data analysis. Content analysis would be a reasonable choice among the standard approaches available for the analysis of the qualitative data, but that decision was not stated. Secondly, to ascertain the presence and/or rule out differences in beliefs that may exist among the women in the three counties, a comparative approach is recommended when data analyses begin.

A subsample of data collected was made available for evaluation. This subsample of the revised instruments, provided some clues about the design and delivery of interventions that should be favorable to the development of "messages" conducive to fostering the development of breast health beliefs that favor early intervention and/or prevention, i.e.,

Item #34, the checklist on "ways in which the interviewee got information about breast cancer" was not a source of qualitative data, but was nevertheless a useful addition to the original battery of data collection instruments. This instrument can be especially useful in facilitating decisions about the best means of transmitting messages intended for intervention and/or prevention.

Item #36, on "faith and the patient's" perspective on cancer. May be a useful quantitative measure of the relationship between faith or religion and approaches to the treatment and/or prevention of cancer.

From the wording of the comments (representing subjects) on some of the instruments designed to collect qualitative data, it is clear that the written data were recorded by the interviewer or another party, other than the interviewee. For those cases, it becomes questionable whether or not the recorded qualitative data are accurate representations of the cognitions, affects, attitudes or health beliefs of the patient-subjects versus the filtered perspectives of the interviewer. The interviewer may mean well, but by attempting to function as both observer and rapid recorder will, in the process of recording be open to the risk of intrusion of his/her own value biases, personal fears and beliefs about cancer, as well as selective perception, memory, misperception of details about the substance of the interviewee's responses, including nuances in meanings important to the patient-subject. Finally, the interviewer-recorder may also be influenced by fatigue, distractions induced by environmental noises and other factors. Consequently, the record of the data collected may confuse and yield insights about the interviewer that are difficult to disentangle from those about the interviewee. One of the best corrections for these risks is to collect the qualitative data (especially the open ended interview data) by audiotape recorder. This procedure will yield a much more accurate and richer body of qualitative data for subsequent analysis. While audiotapes of these interviews were not provided at the time of this evaluation, fortunately, these tapes are available for each interview.

V. CONCLUSIONS

After having gotten off to a difficult start, the Year 01 of the Breast Health Belief Systems Study ended with many successes: a multidisciplinary research team was established that included lay persons as key members of the team; partnerships with community-based agencies were formed which will be most beneficial in the intervention phase of the project; 61 qualified subjects were enrolled in the study with at least 31 more who are interested in being on the registry; ethnographic data collection will be completed by the end of September (month 2 of Year 02). Analysis of data is incomplete at this time, therefore, no conclusions can be reached about the hypothesis, regarding Objective One of the study.

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BREAST HEALTH BELIEF SYSTEMS STUDY
Personal Information Questionnaire

Subject ID:______________________________
Interview Date:___________________________
Last Name, First Name of Subject:____
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. 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)

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

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

8. Have you ever lived anywhere other than Georgia? _____No ____Yes

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

9. 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)__________

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?____

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
_____between $10,000 and $20,000
_____$20,000 - $30,000
_____ above $30,000
_____don't know

14. 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

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

16. 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

17. If you have medical insurance how much do you pay? ____________

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

19. Who told you?

20. How many times have you been pregnant?________

21. Do you still get your period? ____Yes _____No
If yes, do you use any kind of birth control methods?
If yes, what kind?____________________________

22. 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

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

27. Have you had a hysterectomy?_____Yes _____No

28. Do you take hormone pills?_____Yes _____No

29. Other than breast cancer, have you had any other kind of cancer? _____Yes _____No
If yes, what kind(s)?______________________________

30. Do you have any relatives who have had cancer? ____Yes _____No

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

____
____
____
____
____

Thank you very much for your assistance.

ID#______ **PROBES**

BREAST HEALTH BELIEF SYSTEMS STUDY
INTERVIEW SCHEDULE

Interview Date:______________
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.

1. Tell me about your experiences with breast cancer.

Sequence of Events

Symptoms

Treatment

Social Support

Use back of this page if needed.

ID#______ **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

____ **Reasons for**

____ **choosing**

____ **person.**

____

____ **Details of**

____ **what they**

talked about

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

____

____ **Behavior**

____

____ **Stigma**

____

____ **Advice**

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

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

5a. Why did you wait?
   If over two weeks.

____

____

____

6. Did you ever think you would get breast cancer? ____Yes____No
   Explain.

____

____ **Why?**

____

____

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

____

____

____

____

ID#______ **PROBES**

8. What do you think caused your breast cancer?

____
____
____

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

____
____
____
____
____

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

____
____

11. Prior to your diagnosis of breast cancer did you go to thedoctor on a regular basis?
___Yes___No. Why or why not?
Skip if in narrative

____
____
____

12. Do you go to the doctor on a regular basis now?_____Yes_____No
Why or why not?

____
____
____

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?

____
____ **Detail both**
____ **good & bad**
____ **experiences**
____
____ **Type of**
____ **doctor**
____
____ **Race**
____
____ **Gender**
____

ID#______

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?

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?

16b. If no, why not?

17. How did you feel about touching your breasts?

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

ID#______ **PROBES**

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.

____
____
____

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.

____
____

23. Do you think that high blood or low blood can cause cancer? ___Yes ___No
Explain.

____
____
____

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

____**Drugstore**
____**Teas**
____**Roots**
____**Herbs**

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

____
____ **Beliefs**
____
____ **Healing**
____
____ **Surviving**
____
____ **Minister**
____
____ **Church**
____ **Groups**
____
____ **God**
____
____ **Scripture**
____
____ **Sermons**
____

ID#______ **PROBES**

26. What advice have you ever offered to others about breast cancer?
What did you tell them?

____
____ **Treatment**
____ **Prevention**
____ **Causes**

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

____
____
____
____

28. Before your diagnosis of breast cancer, how did you describe breast cancer?

____
____
____
____
____

29. What would you have done differently to prevent and treat your breast cancer?

____
____
____
____
____

30. Do you think breast cancer is curable?____Yes ____No

31. 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?____

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

	Yes	No
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.	____	____

ID#______ **PROBES**

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

____ **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 <u>before</u> 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		

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

____

____

____

____

____

ID#______

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.			
You would trust more in God to cure your cancer than medical treatment.			
You would refuse medical treatment and trust only in God to cure cancer.			
Only a religious miracle treatment could cure your cancer, not medical treatment.			
Your cancer would be because you had sinned against God.			
It would be your responsibility to pray every day that God would cure your cancer.			
The strength of your own faith in God would determine if your cancer was cured.			
Your prayer alone would do nothing to cure your cancer.			
You would want your church members to come to the hospital to pray with you.			
Your church members praying in church would help to cure your cancer.			
There would be a special ceremony for you in your church to cure your cancer.			
You would not tell anyone in your church about your cancer.			
You would not ask people in church to pray for you.			

ID#________

OBSERVATIONS

ID#________

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:

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

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

PILE SORTS

I am going to give you a set of cards. Please look at the words and phrases on these cards and make piles of the words and phrases that are most alike. You can make as many piles as you wish. After you make the piles, I will ask you why you put the words and phrases in each pile together.

ID#______

SYMPTOMS

Pile 1	Pile 2	Pile 3	Pile 4	Pile 5	Pile 6	Pile 7

REASONS

Pile 1:

Pile 2:

Pile 3:

Pile 4:

Pile 5:

Pile 6:

Pile 7:

ID#______

CAUSES

Pile 1	Pile 2	Pile 3	Pile 4	Pile 5	Pile 6	Pile 7

REASONS

Pile 1:

Pile 2:

Pile 3:

Pile 4:

Pile 5:

Pile 6:

Pile 7:

ID#______

TREATMENTS

Pile 1	Pile 2	Pile 3	Pile 4	Pile 5	Pile 6	Pile 7

REASONS

Pile 1:

Pile 2:

Pile 3:

Pile 4:

Pile 5:

Pile 6:

Pile 7:

ID#______

OBSERVATIONS

APPENDIX B

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%)
BreasTest/BreastTest 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.