GRANT NUMBER DAMD17-96-1-6271

TITLE: An Intervention Study on Screening for Breast Cancer Among Single African-American Women Aged 65 and Older

PRINCIPAL INVESTIGATOR: Kangmin Zhu, Ph.D.

CONTRACTING ORGANIZATION: Meharry Medical College
Nashville, TN 37208

REPORT DATE: September 1997

TYPE OF REPORT: Annual

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

DISTRIBUTION STATEMENT: Approved for public release; distribution unlimited

The views, opinions and/or findings contained in this report are those of the author(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.
An Intervention Study on Screening for Breast Cancer Among Single African-American Women Aged 65 and Older

Kangmin Zhu, Ph.D.

Meharry Medical College
Nashville, TN 37208

Commander
U.S. Army Medical Research and Materiel Command
Fort Detrick, Frederick, Maryland 21702-5012

This is a community-based intervention study that aims to develop and evaluate an intervention program on breast screening according to the characteristics of older single African-American women. Study subjects are single African-American women ages 65 and older living in the public housing complexes in Nashville. The complexes are randomly assigned to the intervention or control group. As of August 31, 1997, we have conducted pre-intervention interviews with 232 recruited women. The lay health educators have delivered the intervention to 123 women in the intervention group to improve their breast screening behavior and emotional adjustment skills. Educational materials were mailed to 241 significant others of the women in the intervention group. The significant others were advised to help the women by providing health information, advising a breast screening, increasing emotional support, and giving other needed help. More interviews and intervention deliveries are under way. Through the collective efforts, this study has progressed very well in terms of the statement of work, especially considering that the research team was fully staffed only several months ago. Once interviews at pre-intervention are completed, data will be analyzed to examine the barriers to breast screening and emotional problems among the older single African-American women.
Opinions, interpretations, conclusions and recommendations are those of the author and are not necessarily endorsed by the U.S. Army.

Where copyrighted material is quoted, permission has been obtained to use such material.

Where material from documents designated for limited distribution is quoted, permission has been obtained to use the material.

Citations of commercial organizations and trade names in this report do not constitute an official Department of Army endorsement or approval of the products or services of these organizations.

In conducting research using animals, the investigator(s) adhered to the "Guide for the Care and Use of Laboratory Animals," prepared by the Committee on Care and Use of Laboratory Animals of the Institute of Laboratory Resources, National Research Council (NIH Publication No. 86-23, Revised 1985).

For the protection of human subjects, the investigator(s) adhered to policies of applicable Federal Law 45 CFR 46.

In conducting research utilizing recombinant DNA technology, the investigator(s) adhered to current guidelines promulgated by the National Institutes of Health.

In the conduct of research utilizing recombinant DNA, the investigator(s) adhered to the NIH Guidelines for Research Involving Recombinant DNA Molecules.

In the conduct of research involving hazardous organisms, the investigator(s) adhered to the CDC-NIH Guide for Biosafety in Microbiological and Biomedical Laboratories.

[Signature]

PI - Signature 9/1/97

Date
# Table of Contents

- Introduction ......................................................... 5
- Body ..................................................................... 6
- Conclusions .............................................................. 19
- References ............................................................... 20
- Appendices ............................................................... 21
INTRODUCTION

This is an annual report regarding our intervention study that aims to improve the breast screening behavior among single (windowed, divorced, separated or never-married) African-American women ages 65 and older. This report covers the period from September 1, 1996 to August 31, 1997.

It was the first year of the study. Therefore, tremendous efforts had to be made to establish the study field, to make various preparations, to select study subjects and to initiate interviews. The award notification from the Department of Grants and Contracts Administration, Meharry Medical College, was received by the principal investigator on September 2, 1996. Upon the receipt of the award notification, the principal investigator, Dr. Zhu, began a series of preparations for the study, such as developing the educational brochures and quality control related documents, polishing the questionnaire, working on the IRB and budget related issues and hiring research team members. Due to the position-control and employment process and procedures of Meharry and the selection process, the research specialist (research coordinator) and the research assistants were able to be on board in February, April and May, 1997, respectively. The Research Specialist, Ms. Sandra Hunter immediately began coordinating procedures for the project and has done a wonderful job. She performed pre-interviews with selected women to test the questionnaire and gain their feedback and comments. She also handled miscellaneous affairs for the study, including ordering supplies, contacting study field coordinator, recruiting lay health educators and study helpers, working on various forms and documents needed for the study and helping with hiring research assistants. The research
assistants, Ms. Kathleen Payne-Wilks and Ms. Chanel Roland, joined in the preparation process. They received training on the interview skills, knowledge of breast health and study quality control. During the study, they have developed a very good cooperative relationship with lay health educators and study helpers, overcome various difficulties, and done an outstanding job with the in-person interviews. With great enthusiasm, the lay health educators of the study have been very cooperative and done terrifically in the education of study subjects on the intervention components.

According to the Statement of Work, pre-interviews would be completed at the end of 15\textsuperscript{th} month of the project. Until August 31, the project had been going for 12 months, with the interviewers on board in April and May. During the period, the project has progressed very well. The research team has done a lot of preliminary work, 232 interviews, and 123 interventions. However, since the pre-intervention interviews have not been completed and the data collected are being entered into computer, we currently do not have the questionnaire-based results available for this report. The following is the summary of the work done up to August 31.

**BODY**

1. Study Hypothesis

This study is based on the hypothesis that older single (widowed, divorced, separated or never-married) African-American women have the highest risk of not utilizing breast screening, because of their poorer social, familial, economic, and psychological/behavioral characteristics.
Therefore, they benefit most from an effective intervention program on screening for breast cancer. This study aims to develop and evaluate an intervention program on breast screening according to the characteristics of older single African-American women.

2. Study Design

This study uses a community-based intervention design. Study subjects are single African-American women ages 65 and older living in eight public housing complexes in Nashville, Tennessee. The complexes are stratified according to the proportion of older African-Americans and randomly assigned to the intervention or control group (4 complexes in each group). An intervention program increasing breast screening knowledge, psychological health and support from significant others is performed for the intervention group. Interventions on study women are delivered by lay health educators, using didactics, modeling and brochures. Mailed educational materials are used for interventions on the significant others. Pre-intervention, post-intervention and follow-up interviews are conducted to evaluate the effect of the intervention program.

3. Methods and procedures implemented for the study

3.1. Identification of study subjects

Ms. Peaches Manning is the resident coordinator of the Metropolitan Development and Housing Authority (MDHA) of Nashville. She also is the collaborator of the study. Before the
study, our research-team members had meetings with Mrs. Manning to discuss detailed procedures to recruit study women. As the first step, we chose eight complexes with more African-Americans aged 65 and older as study fields. Then, a list of addresses of all African-American ages 65 and older was provided by MDHA. Door-to-door canvassing strategy is taken to identify the eligible women and to recruit them for the study. The door-to-door canvassing is conducted by a lay health educator or study helper (see below) identified from the complex and a female research interviewer with African-American ethnicity.

With a letter from Mrs. Manning and a letter from the principal investigator (appendix 1), the lay health educator (intervention sites) or study helper (control sites) and the research interviewer visit each address to identify eligible women according to ethnicity, age, marital status and history of breast cancer. If a woman is eligible, the lay health educator and the interviewer further introduce the study and its procedures, mention monetary incentive and obtain the woman’s consent to participate in the study. For an eligible woman who is willing to participate and sign the consent form, an in-person interview is conducted immediately if she is available at the visit or scheduled if she is not available then. If an individual at the address is not home at the visit, subsequent visits will be made to identify the eligibility. The same efforts will be made to complete an interview for a woman who is not home at a scheduled time.

Eight complexes chosen for the study were Hadley Towers, J.C. Napier Court, Tony Sudekum Homes, Cheatham Place, Preston Taylor Homes, John Henry Hale Homes, Andrew Jackson Court, and I.W. Gernert. These housing complexes were randomly assigned to the intervention or control group. There were six hundred and twenty-seven addresses, from the
complexes, identified as having residents aged 65 and older (including both males and females).

3.2. Identification of study helpers and lay health educators

Mrs. Manning has given us great help in providing the addresses of older residents and the recruitment of lay health educators or study helpers. She identified from each complex a woman eligible for being a lay health educator or study helper and made an initial contact with the woman about the possibility for her to work for the study. After a woman was recommended as a lay health educator or study helper, she had a meeting with our research team members. We talked to the woman about the study project and work procedures, and responsibilities and benefits as a lay health educator or study helper, and asked her willingness to be such an person. An eligible woman who would work as a lay health educator or study helper signed a contract with the principal investigator, and subsequently works among women in the complex where she lives.

In the original design, we proposed recruiting African-American women aged 51-59 as a lay health educator. Ms. Manning and Mrs. Hunter made great efforts to identify and recruit lay health educators according to the criteria. However, based on a woman’s willingness and availability, the criterion on age was not met in some housing complexes. As a result, four African-American ladies aged 69, 68, 52 and 39, respectively, were recruited as lay health educators. Our training sessions and interventions completed showed that these lay health educators, despite their different ages, well understood the training materials, learned the intervention skills and can execute the intervention well.
The original proposal did not include the use of study helpers for control group. We added this component during the execution of the study. The reasons for doing so are twofold: (1) safety considerations and (2) obtaining higher participation rate of eligible women. A study helper from the control complex where she lives can serve as a familiar face when the interviewer visits identified homes, reducing the possible distrust and increasing the participation.

3.3. Test and revisions of the questionnaire

Ms. Hunter performed pre-interview test with five African-American women to gain feedback concerning the questionnaire. These women represented the various backgrounds including breast cancer patients, nurse, home wife, engineer and customer service representative. All the participants agreed that the questions are suitable and the women would feel comfortable with the questionnaire. However, they recommended changing the order of the questions for further improvement. They suggested that the questionnaire begin with more soft questions (i.e. background, social network) and put more direct questions (i.e. medical history) later. Based upon the comments from the pre-interview test, revisions were made to the questionnaire (appendix 2). This helped the subjects feel more at ease with the interview process.

3.4. Design, making and printing of brochures

As we mentioned before, the brochures for the study would be made based on
appropriateness of ethnicity, old age, low income, and single marital status. We used words and graphs that are relevant to African-Americans, and African-American role models in the brochures. We used in printed materials large and clear typefaces and graphics reflecting lives of older African-American women. We made effort to have the text brief, and easy to understand. The printed educational materials were designed to be bright and luminous.

Ms. Tao, an artist who is interested in the study, helped us with superb artistic work for the brochures on breast health and psychological adjustment. Ms. Lee and Ms. Gupton volunteered to be models for the picture for the brochure for significant others, and they had many pictures taken for the brochure. During the production of the brochures, we obtained great support and help from enthusiastic people. Due to the invaluable support and help, it has made it possible for us to develop high-quality brochures (appendix 3).

The high quality of the brochures was achieved also by our effort and procedures for the goal. Dr. Zhu drafted the text of all brochures that was reviewed and commented by Ms. Hunter with experience in making brochures. To further ensure the appropriateness, the drafted brochures were also reviewed by other African-American health professionals and African-American women. Improvement was made in terms of their comments. After the final version was obtained, Ms. Hunter and Dr. Zhu diligently worked with the artist, the model women and the producer on the design, format, production and copy of the brochures, trying to achieve the high quality with very limited budget.

3.5. Training of lay health educators
For interventions on study subjects, we will use didactic and modeling techniques to teach study subjects on breast cancer knowledge, benefits of breast cancer screening, psychological coping skills, increasing social activities and seeking social support. Brochures addressing all intervention components are given to study women for their future use. These intervention components are delivered by lay health educators.

To perform the intervention effectively, we provided four 3-hour training sessions for training lay health educators. Session 1 involved the basic knowledge of breast cancer including pathogenesis, natural history, and epidemiology of the disease, and knowledge of breast cancer screening procedures and their benefits. Session 2 talked about barriers to the screening procedures, and how to implement education by using didactic and modeling techniques. Session 3 covered psychological characteristics of single women, psychological adjustment and coping skills. Session 4 was about how to perform psychological education using didactic and role-modeling skills and gave lay health educators an opportunity to practice the skills they have learned and to perform interventions in a simulated situation. The first two hours of each session were teaching, and the third hour was the time for questions and discussions. Important issues were addressed, repeated, and summarized during the training. At the end of each session, a short test was given to the session attendants to ensure that they have comprehended what had been taught in the session. To make sure that every lay health educator learned the educational skills and can perform education effectively, one (or two when necessary) individual session(s) was held. In this session(s), our research-team member worked with the lay health educator to imitate an intervention process until a satisfactory performance could be achieved.
Dr. Louis Bernard (oncologist and surgeon), Dr. Lloyd Elam (psychiatrist) and Dr. Zhu (epidemiologist) gave the lectures in their respective field. With the involvement of the research team members, Drs. Bernard and Elam taught lay health educators intervention skills in improving breast health/screening and coping with emotional problems, respectively. We prepared a written script for the lay health educators to use as a guideline during the role playing and teaching.

To maximize the attendance to the training sessions, we provided the identified lay health educators with juice, lunch and transportation when needed, and paid them for their attendance. During the sessions, an informal and relaxed atmosphere was created for the effective interactions between the instructor and attendants. The attendants sat with the instructor around a table to receive training, ask questions and practice the intervention skills they have learned, except for during the lectures for which slides and transparencies are needed. The attendants were asked about their experiences on breast screening and psychological adjustment, and were encouraged to tell the positive experience when they conduct the interventions. Four lay health educators received the training. All of them passed the test and can execute an intervention well. All of the lay health educators were very satisfied with the content and implementation of our training sessions.

3.6. Training of interviewers

Interviewers attended all sessions for the lay health educators. In addition, two 2-3 hour
sessions were provided on interviewing/recording/editing skills, introducing the questionnaire, defining/clarifying questions and answers, and mimicking interview process. Other issues for a good interview and communication with women, such as interviewer’s appearance, ways to approach women, introduction remarks, ways to deal with difficult situations and so on, were also addressed. An overview of interview procedures and a brief interview guideline were provided as the guidance for interviews (appendix 4).

3.7. Study quality control

A. Training interviewers and lay health educators in study quality control: Interviewers were trained to improve their performance in reducing under-reporting of information and item non-response, avoiding inductive questioning and evading inferring from an incomplete or inadequate reply. They were asked to examine a completed form immediately after an interview for any errors, inconsistencies, unusual answers and missing values, and to make corrections or compensations where possible. Lay health educators were trained on correctly using intervention skills taught and fulfilling each intervention component needed. An operational manual was developed as a guide of didactic and modeling interventions.

B. Monitoring and evaluating interview and intervention implementations: For the fidelity of interviews and implementation of interventions, we asked interviewers and health educators to record the process of an interview or an in-person education, using a cassette recorder. Recording tapes were randomly reviewed for quality control purpose. To evaluate the quality of the intervention execution, the interviewer observes the lay health educator’s
performance during the intervention and completes an evaluation form at the end of the intervention. This form contains date, time length of intervention execution, lay health educator’s implementation, and subject’s interests, understanding and acceptance of each intervention component (appendix 5).

C. Research administration: In addition to day-to-day communications on the research activities, we established a weekly-meeting system. In the meeting, the progress of the past week was summarized. All research members are asked to present and discuss any potential problems and good experiences in keeping a good working relationship with lay health educators or study helpers and in communications with study women. This is important for implementing effective intervention and increasing the participation of eligible women. Mrs. Sandra Hunter, research specialist, arranges all data collection activities and examines and maintains all data to avoid or reduce any overlapping, missing or inaccuracy. In addition, a subject tracking system was developed to integrate data from the different sources (appendix 6).

D. Reducing inter-interviewer variations: The complexes in intervention and control groups were equally assigned to the two interviewers so that each interviewer can interview approximately the same number of women for each group. It can reduce the effect of inter-interviewer variations that may lead to a systematic bias when an interviewer is primarily responsible for interviews in one group.
4. Current status of study

4.1. Participation rate of eligible women: Up to August 31, five hundred and sixty homes have been visited with 297 eligible women identified and 232 interviewed. Table 1 lists the number of addresses, the number of eligible women, the number of refusals, the number of interviews completed and the number of remaining homes for visit according to the complex.

One hundred and thirty-nine women in the control group (J.C. Napier Homes, Hadley Park Towers, Tony Sudekum Homes, Andrew Jackson Courts) were identified as eligible and 78.4% of these women would participate in the study. The corresponding numbers were 157 and 78.3% for the intervention group (John Henry Hale, Cheatham Place, Preston Taylor Homes, I.W. Gernert Homes). The participation rates were relatively high, compared with those in the study in Atlanta (Blumenthal et al, 1995). In this study, only 38.5% of women identified from the patient registration log of a medical center would participate. The participation rate was 47.7% for women identified from public housing projects, business establishments and churches. We believe that our recruitment strategies including monetary incentives have been effective in recruiting study subjects, and our interviewers, Mrs. Roland and Payne-Wilks, have done a great job in recruiting and interviewing study women.
Table 1. The numbers of addresses, eligible women, refusals, interviews completed and the remaining homes for visit according to complex, as to August 31, 1997

<table>
<thead>
<tr>
<th>Housing Complex</th>
<th># of Addresses</th>
<th>Current Ineligible #</th>
<th>Current Eligible #</th>
<th>Current Refusal</th>
<th>Interviews</th>
<th>Completed</th>
<th>Remaining Addresses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hadley Towers</td>
<td>96</td>
<td>51</td>
<td>45</td>
<td>7</td>
<td>38</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>J.C. Napier Court</td>
<td>64</td>
<td>22</td>
<td>41</td>
<td>13</td>
<td>28</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Tony Sudekum Homes</td>
<td>20</td>
<td>1</td>
<td>11</td>
<td>2</td>
<td>9</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Cheatham Place</td>
<td>86</td>
<td>46</td>
<td>36</td>
<td>9</td>
<td>27</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Preston Taylor Homes</td>
<td>37</td>
<td>11</td>
<td>26</td>
<td>4</td>
<td>22</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>John Henry Hale Homes</td>
<td>54</td>
<td>26</td>
<td>28</td>
<td>5</td>
<td>23</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Andrew Jackson Court</td>
<td>136</td>
<td>43</td>
<td>42</td>
<td>8</td>
<td>34</td>
<td>51</td>
<td>6</td>
</tr>
<tr>
<td>I.W. Gernert</td>
<td>136</td>
<td>63</td>
<td>67</td>
<td>16</td>
<td>51</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>629</strong></td>
<td><strong>262</strong></td>
<td><strong>296</strong></td>
<td><strong>64</strong></td>
<td><strong>232</strong></td>
<td><strong>70</strong></td>
<td></td>
</tr>
</tbody>
</table>
4.2. Interviews: Two hundred and thirty-two interviews have been conducted up to August 31. To ensure that the interviews were satisfactory to study women (that is important for them to accept post-intervention and follow-up interviews), we randomly called 9 women about their feeling concerning the interview, after interviewers executed the first 20-30 interviews. Except one woman who said “the interview was alright”, all other women enjoyed the interview or thought that the interview was good or pretty good.

4.3. Intervention implementation: The interventions were delivered to 123 women in the intervention group up to August 31, 1997. Based on the intervention evaluation forms, 97.5% of interventions on breast health were very good and the rest of them (2.5%) were good. The corresponding percentages were 98.4% and 1.6% for interventions on emotional adjustment. About ninety-four percent of women were interested in the teaching on breast health and emotional adjustment, respectively. Ninety-six percent of women seemed to understand the intervention content.

4.4. Intervention on significant others: Once the interventions were completed, we sent a packet containing a cover letter (appendix 7), educational brochure (appendix 8) and support agreement to each of women’s significant others. Although most study subjects identified three significant others as asked during the interview, some of them could identify only one or two. One difficulty was that most subjects did not know the exact addresses of their significant others. Therefore, extra efforts had to be made to find the correct addresses through phone book or telephone calling.
Two hundred and forty-one significant others of 123 women were sent a mail in August. Up to August 31, twenty-eight significant others returned the completed support agreement to show their willingness to help study women with getting breast screening and provide emotional support. More responses from the significant others are coming.

4. Recommendations in relation to the statement of work

According to the statement of work, pre-intervention interviews would be completed at the end of the fifth month of the project. The current progress is consistent with that in the statement of work, with 232 women interviewed at the end of 1st year. However, we estimate that only 280-300 women from the eight housing complexes would be included in the study when the pre-intervention interviews are completed, which is less than that we expected (400). Therefore, we are considering recruiting more women in the study. We will choose two additional complexes with relatively more eligible African-American women from the remaining housing areas. An additional 50-70 interviews may be obtained from these two housing complexes.

CONCLUSIONS

As of August 31, 1997, the project staff has finished work designated in the statement of work. The research team members have worked diligently on developing project-related documents, identifying and recruiting study subjects, interviewing with study women, establishing and managing computer files, and implementing quality control procedures. Ms.
Manning, the resident coordinator of the Metropolitan Development and Housing Authority (MDHA) of Nashville, has provided us great helps in identifying eligible women, lay health educators and study helpers. The lay health educators of the study have done well in the delivery of the interventions on breast screening behavior and emotional adjustment.

As a result of the collective efforts, we currently have recruited and completed interviews with 232 single African-American women aged 65 and older. The interventions on breast screening and emotional adjustment have been delivered to 123 women in the intervention group. As one of the intervention components, we have sent to 241 significant others of the women in the intervention group a packet containing an educational brochure and the support agreement to. More interviews and interventions are being conducted for the study.

Because the number of participants may be lower than expected, we plan to add two other housing complexes to the study. As long as interviews at pre-intervention are completed, data will be analyzed. We expect that data from the interviews will provide more information on the barriers to breast screening and psychological status among older single African-American women.

REFERENCES

APPENDICES

1. Letters to subjects
2. Questionnaire
3. Brochures for study subjects
4. Overview of interview procedures and interview guidelines
5. Intervention evaluation form
6. Flowcharts for tracking system
7. Letter to significant others
8. Brochure for significant others
Dear Madam:

We are writing to ask for your participation in an important study on preventive health care and related factors among African-American women. This study will contribute to the improvement of African-American women’s health status. The Metropolitan Development and Housing Agency has given us approval to contact you for this study.

The study will consist of a 25-30 minute in-person interview once a year for the next three years. If you agree to participate in the study, you will be paid $25.00 for each completed interview. To participate, please sign the enclosed consent forms and keep one copy for your file and return the other copy to the research assistant.

Your participation in this study is completely voluntary. Whether or not you choose to participate will have no effect on any future health care from any institution or any rights as a resident in the Public Housing Development to which you are entitled. All information collected will be kept strictly confidential as required by law. Your name will not appear on any reports, it will be used only for the purpose of payment.

We hope you are willing to take part in this study, because the validity of this study will be strengthened if all persons we contact do participate. If you have any questions, please call Ms. Hunter at (615) 327-6890, between 7:30 a.m. and 4:30 p.m., Monday through Friday. Thank you very much for your time and consideration.

Sincerely,

Kangmin Zhu, M.D., Ph.D.
Principal Investigator
Dear Madam:

We are writing to ask for your participation in an important study on preventive health care and related factors among African-American women. This study will contribute to the improvement of African-American women’s health status. The Metropolitan Development and Housing Agency has given us approval to contact you for this study.

The study will consist of a 25-30 minute in-person interview once a year for the next three years. If you agree to participate in the study, you will be paid $25.00 for each completed interview. In addition, a lady from your neighborhood will deliver and explain some brief brochures that are beneficial to your health, following the first interview. We will pay you an additional $15.00 for your acceptance of the education. To participate, please sign the enclosed consent forms and keep one copy for your file and return the other copy to the research assistant.

Your participation in this study is completely voluntary. Whether or not you choose to participate will have no effect on any future health care from any institution or any rights as a resident in the Public Housing Development to which you are entitled. All information collected will be kept strictly confidential as required by law. Your name will not appear on any reports, it will be used only for the purpose of payment.

We hope you are willing to take part in this study, because the validity of this study will be strengthened if all persons we contact do participate. If you have any questions, please call Ms. Hunter at (615) 327-6890, between 7:30 a.m. and 4:30 p.m., Monday through Friday. Thank you very much for your time and consideration.

Sincerely,

Kangmin Zhu, M.D., Ph.D.
Principal Investigator
May 23, 1997

Dear Resident:

The Metropolitan Development and Housing Agency is in collaboration with Meharry Medical College for an important survey on the health of single African-American women ages 65 and older. I am writing to ask for your help for this survey.

For that reason, two ladies will visit your home to ask for your participation. If you agree to participate, a lady will ask you some health-related questions once a year during the next three years. Each interview will take about 30 minutes and you will be paid $25 for each interview completed.

Your participation in this study is voluntary. All information received will be kept strictly confidential as required by law. We hope you will participate in this survey aimed at improving African-American Women’s Health.

Your support for this important research study on African-American Women’s Health is very important and will be appreciated. If you have any questions concerning this letter, please contact Ms. Hunter at 327-6890 or me at 252-3698.

Sincerely,

Peaches Manning
Resident Association Coordinator

PM:lst

C:/lst/peaches/AAW-health.doc
May 23, 1997

Dear Resident:

The Metropolitan Development and Housing Agency is in collaboration with Meharry Medical College for an important survey on the health of single African-American women ages 65 and older. I am writing to ask for your help for this survey.

For that reason, two ladies will visit your home to ask for your participation. If you agree to participate, a lady will ask you some health-related questions once a year during the next three years. Each interview will take about 30 minutes and you will be paid $25 for each interview completed. In addition, a lady will teach you some knowledge on women’s health for an additional 30 minutes after the first interview. An extra $15 will be paid to you.

Your participation in this study is voluntary. All information received will be kept strictly confidential as required by law. We hope you will participate in this survey aimed at improving African-American Women’s Health.

Your support for this important research study on African-American Women’s Health is very important and will be appreciated. If you have any questions concerning this letter, please contact Ms. Hunter at 327-6890 or me at 252-3698.

Sincerely,

[Signature]

Peaches Manning
Resident Association Coordinator

PM:lst

C:/lst/peaches/AAW-health.doc
<table>
<thead>
<tr>
<th>Study ID</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>PHR#</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interviewer ID</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date of Interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time Interview Begin</td>
<td></td>
<td>a.m./p.m.</td>
</tr>
<tr>
<td>Time Interview Ended</td>
<td></td>
<td>a.m./p.m.</td>
</tr>
<tr>
<td>Reference Date</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**WOMEN'S HEALTH STUDY**

(IS-1-1)

Meharry Medical College
Family & Preventive Medicine
AT THE DOOR:

Hello, my name is (YOUR NAME). I am from Meharry Medical College. I am here to speak with (NAME OF RESPONDENT).

IDENTIFY ELIGIBILITY,
INTRODUCE THE STUDY AND THE RESPONDENT'S RIGHTS,
OBTAIN THE CONSENT, AND
ARRANGE PRIVATE SETTING FOR INTERVIEW.

TO BEGIN THE INTERVIEW:

Ms. (NAME OF RESPONDENT), I would like to begin asking you questions related to the study. I would like to repeat that your information will be kept completely confidential as required by law, and you also may refuse to answer any questions.

SECTION A: BACKGROUND INFORMATION

First, I would like to ask some questions about your background.

A1. What is your date of birth?

   ___/___/____
   (month, day, year)

A2. Have you ever been married or lived as married?

   No ........................................... 0
   Yes ........................................... 1

A3. What was your marital status in the past year?

   Married ..................................... 1
   Separated ................................... 2
   Divorced .................................... 3
   Widowed .................................... 4
   Never married .............................. 5

A4. How many years have you been in this marital status?

   <2 years .................................... 1
   2-4 years .................................. 2
   5-9 years .................................. 3
   >=10 years ................................ 4
   (DO NOT READ)  Not sure .................. 9

A5. Have you ever been employed?

   No ........................................... 0
   Yes ........................................... 1
A6. What was the occupation that you worked in the longest?

__________________________ (occupation) __ __ (code)

A7. What is the highest level of school that you completed?

- No school ........................................... 0
- Elementary school ................................ 1
- Middle school ...................................... 2
- High school ........................................ 3
- Vocational or technical training school ......... 4
- Some college or junior college ................. 5
- College ............................................. 6
- Graduate or professional school ............... 7
- Other (specify) ..................................... 8

(DO NOT READ) → Refused .............................. 9

SECTION B: SOCIAL NETWORK AND SOCIAL ACTIVITIES

B1. How many living children do you have?

__ __ (children)

None ...................... 0

B2. How many living grandchildren do you have?

__ __ (children)

None ...................... 0

B3. Are there any children or grandchildren living in your household?

No .................................................. 0
Yes .................................................... 1

(DO NOT READ) → N/A .................................. 9

B4. How frequently do you see any of your children or grandchildren?

Less than once a year .................. 1
About 1-2 times a year ............... 2
About 3-4 times a year ............... 3
About 5-6 times a year ............... 4
About 7-11 times a year ............. 5
About every month ..................... 6
About once every other week ...... 7
About once a week or more ........ 8

(DO NOT READ) → Not sure ..................... 9
B5. How often do you call any of your children or grandchildren?

- Less than once 6 months ........................................... 1
- About once 2-6 months ............................................. 2
- About every month .................................................. 3
- About once every other week .................................... 4
- About once a week .................................................. 5
- More than once a week ............................................. 6

(DO NOT READ) → Not sure ........................................... 9

B6. If you had financial difficulty, would any of your children or grandchildren give money to you? (READ LIST)

- Definitely ................................................................. 1
- Probably ................................................................. 2
- Maybe .................................................................. 3
- Probably not ......................................................... 4
- Definitely not .......................................................... 5

(DO NOT READ) → Do not know ........................................... 9

B7. If you were feeling ill one day, would any of your children or grandchildren be willing to take you to the hospital or help cook dinner? (READ LIST)

- Definitely ................................................................. 1
- Probably ................................................................. 2
- Maybe .................................................................. 3
- Probably not ......................................................... 4
- Definitely not .......................................................... 5

(DO NOT READ) → Do not know ........................................... 9

B8. How many relatives can you talk to about private matters or can call for help?

____ (relatives)

B9. How often do you see any of these close relatives?

- Less than once a year .................................................. 1
- About once 7-12 months ............................................. 2
- About once 4-6 months ............................................. 3
- About once 2-3 months ............................................. 4
- About once every month ......................................... 5
- About once every other week .................................. 6
- About once a week or more ..................................... 7

(DO NOT READ) → Not sure ........................................... 9
B10. How often do you call any of these close relatives?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than once 6 months</td>
<td>1</td>
</tr>
<tr>
<td>About once 4-6 months</td>
<td>2</td>
</tr>
<tr>
<td>About once 2-3 months</td>
<td>3</td>
</tr>
<tr>
<td>About every month</td>
<td>4</td>
</tr>
<tr>
<td>About once every other week</td>
<td>5</td>
</tr>
<tr>
<td>About once a week</td>
<td>6</td>
</tr>
<tr>
<td>More than once a week</td>
<td>7</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Not sure ........................................ 9

B11. If you had financial difficulty, would any of these close relatives give money to you?

(READ LIST)

<table>
<thead>
<tr>
<th>Likelihood</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely</td>
<td>1</td>
</tr>
<tr>
<td>Probably</td>
<td>2</td>
</tr>
<tr>
<td>Maybe</td>
<td>3</td>
</tr>
<tr>
<td>Probably not</td>
<td>4</td>
</tr>
<tr>
<td>Definitely not</td>
<td>5</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Do not know ...................................... 9

B12. If you were feeling ill one day, would any of these relatives be willing to take you to the hospital or help cook dinner? (READ LIST)

<table>
<thead>
<tr>
<th>Likelihood</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely</td>
<td>1</td>
</tr>
<tr>
<td>Probably</td>
<td>2</td>
</tr>
<tr>
<td>Maybe</td>
<td>3</td>
</tr>
<tr>
<td>Probably not</td>
<td>4</td>
</tr>
<tr>
<td>Definitely not</td>
<td>5</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Do not know ...................................... 9

B13. How many friends can you talk to about private matters or can call for help?

--- (friends)

B14. How frequently do you see any of these close friends?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than once a year</td>
<td>1</td>
</tr>
<tr>
<td>About once 7-12 months</td>
<td>2</td>
</tr>
<tr>
<td>About once 4-6 months</td>
<td>3</td>
</tr>
<tr>
<td>About once 2-3 months</td>
<td>4</td>
</tr>
<tr>
<td>About once every month</td>
<td>5</td>
</tr>
<tr>
<td>About once every other week</td>
<td>6</td>
</tr>
<tr>
<td>About once a week or more</td>
<td>7</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Not sure ........................................ 9
B15. How often do you call any of these close friends?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than once 6 months</td>
<td>1</td>
</tr>
<tr>
<td>About once 4-6 months</td>
<td>2</td>
</tr>
<tr>
<td>About once 2-3 months</td>
<td>3</td>
</tr>
<tr>
<td>About every month</td>
<td>4</td>
</tr>
<tr>
<td>About once every other week</td>
<td>5</td>
</tr>
<tr>
<td>About once a week</td>
<td>6</td>
</tr>
<tr>
<td>More than once a week</td>
<td>7</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Not sure 9

B16. If you had financial difficulty, would any of these close friends give you money?

(READ LIST)

<table>
<thead>
<tr>
<th>Response</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely</td>
<td>1</td>
</tr>
<tr>
<td>Probably</td>
<td>2</td>
</tr>
<tr>
<td>Maybe</td>
<td>3</td>
</tr>
<tr>
<td>Probably not</td>
<td>4</td>
</tr>
<tr>
<td>Definitely not</td>
<td>5</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Do not know 9

B17. If you were feeling ill, would any of your close friends be willing to take you to the hospital or help cook dinner?

(READ LIST)

<table>
<thead>
<tr>
<th>Response</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely</td>
<td>1</td>
</tr>
<tr>
<td>Probably</td>
<td>2</td>
</tr>
<tr>
<td>Maybe</td>
<td>3</td>
</tr>
<tr>
<td>Probably not</td>
<td>4</td>
</tr>
<tr>
<td>Definitely not</td>
<td>5</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Do not know 9

B18. How often did you go shopping in the past year?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than once a month</td>
<td>1</td>
</tr>
<tr>
<td>About once a month</td>
<td>2</td>
</tr>
<tr>
<td>About once every other week</td>
<td>3</td>
</tr>
<tr>
<td>Once a week</td>
<td>4</td>
</tr>
<tr>
<td>2-3 times a week</td>
<td>5</td>
</tr>
<tr>
<td>More than 3 times a week</td>
<td>6</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Not sure 9
B19. How often did you attend social activities such as party, community meeting, or other community activities in the past year?

None ........................................ 0
Less than once a year ..................1
About 1-2 times a year .............. 2
About 3-6 times a year .......... 3
About once a month .............. 4
About 1-3 times a month .......... 5
Once a week or more ............. 6

(DO NOT READ) → Not sure ................. 9

B20. Would you provide the names, addresses, and phone numbers of three family members or relatives or close friends living in Nashville or surrounding areas who are most significant in your life and would give help to you?

<table>
<thead>
<tr>
<th>Name</th>
<th>Sex</th>
<th>Relationship</th>
<th>Address</th>
<th>Phone number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SECTION C: MEDICAL HISTORY AND MEDICAL CARE

Now, I would like to ask you some questions about your medical history and medical care.

C1. Have you ever had lumps or changes in your breasts that were not cancerous (malignant)?

No (go to C4) ...................... 0
Yes ................................... 1

(DO NOT READ) → Do not know ................ 9

C2. How old were you when they were first diagnosed by a doctor? __ __ (age)

Do not remember .................. 99
Not diagnosis by a doctor (go to C4) ........ 00

C3. What was the diagnosis? (SPECIFY) ............................................. __ __ (code)

(DO NOT READ) → Do not know ................ 99
C4. A breast physical examination is when the breast is felt for lumps by a doctor or other health professionals. Have you ever had a breast physical examination?

No (go to C7) ........................................... 0
Yes ....................................................... 1
(DO NOT READ) → Do not know ........................ 9

C5. How many breast physical examinations were performed by a doctor on you in the past year?

___ (examinations)
None ................................................. 0

C6. When did you have your last breast physical examination?

In the past year ...................................... 0
One year ago ........................................... 1
Two years ago ......................................... 2
3-4 years ago ........................................... 3
5 or more years ago .................................. 4
(DO NOT READ) → Do not know ........................ 9

C7. Have you ever heard of a mammogram?

No .......................................................... 0
Yes ........................................................... 1
(DO NOT READ) → Not sure ........................... 9

C8. A mammogram is an X-ray of the breasts taken by a machine that presses against the breast while the picture is taken. Have you ever had a mammogram?

No (go to C11) ........................................... 0
Yes ........................................................... 1
(DO NOT READ) → Do not know ........................ 9

C9. How many mammograms were performed by a doctor on you in the past year?

___ (examinations)
None ................................................. 0

33
C10. When did you have your last mammogram?

<table>
<thead>
<tr>
<th>In the past year</th>
<th>One year ago</th>
<th>Two years ago</th>
<th>3-4 years ago</th>
<th>5 or more years ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Do not know

C11. Do you examine your breasts for lumps or other changes?

<table>
<thead>
<tr>
<th>No (go to C13)</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Do not know

C12. About how often do you examine your breasts for lumps?

<table>
<thead>
<tr>
<th>Yearly or less</th>
<th>About twice a year</th>
<th>About 3-5 times a year</th>
<th>Every 2 months</th>
<th>Monthly</th>
<th>More often than monthly, less often than weekly</th>
<th>Weekly or more often</th>
<th>Other (SPECIFY)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Do not know

C13. Do you have any type of medical insurance?

<table>
<thead>
<tr>
<th>No (go to C15)</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Do not know

C14. What type of insurance do you have? (READ LIST)

<table>
<thead>
<tr>
<th>TennCare</th>
<th>Medicare</th>
<th>Commercial insurance like Blue Cross</th>
<th>Health maintenance organization or prepaid group practice like Health America</th>
<th>Other (SPECIFY)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
C15. Is there a particular doctor’s office, clinic, health center or other place that you usually go to if you are sick or need advice about your health?

No (go to C17) ................. 0
Yes .................................. 1
(DO NOT READ) → Do not know .................................... 9

C16. How far is your home from this medical facility?

______ (miles)

C17. Is there a transportation tool available when you need to go to see a doctor?

No ..................................... 0
Yes ...................................... 1
(DO NOT READ) → Do not know .................................... 9

C18. Do you have a doctor you consider to be your regular doctor?

No (go to C21) ...................... 0
Yes ...................................... 1
(DO NOT READ) → Do not know .................................... 9

C19. What kind of doctor is he/she? (READ LIST)

A medical doctor (family doctor, internal medicine, etc.) ............................................. 1
A gynecologist ........................................................................................................ 2
A specialist (SPECIFY) ......................................................................................... 3
Other (SPECIFY) ................................................................................................. 4
(DO NOT READ) → Do not know ............................................................... 9

C20. Has he/she ever advised you to have a mammogram?

No ......................................... 0
Yes ......................................... 1
(DO NOT READ) → Do not know ............................................................... 9

C21. Did you see a doctor on a regular basis?

No ......................................... 0
Yes ......................................... 1
(DO NOT READ) → Not sure ............................................................... 9
C22. Have any doctors you visited ever advised you to have a mammogram?

- No .............................................. 0
- Yes ............................................. 1

(DO NOT READ) → Do not know ........................................ 9

C23. How often have you visited a doctor within the past five years?

- None ............................................. 0
- Less than once a year .......................... 1
- One to two times a year ......................... 2
- Three to five times a year ....................... 3
- One to two times a month ...................... 4
- More than once a month ....................... 5

(DO NOT READ) → Do not know ........................................ 9

C24. Did you have any medical problem or disability that impeded your visiting a doctor in the past year?

- No .............................................. 0
- Yes ............................................. 1

(DO NOT READ) → Do not know ........................................ 9

SECTION D: FAMILY HISTORY

D1. I would like to ask history of breast cancer among your family members, relatives or close friends. Were (or was) any of your (READ EACH TYPE OF RELATIVES OR CLOSE FRIENDS SEPARATELY) diagnosed with breast cancer by a doctor?

<table>
<thead>
<tr>
<th>Type</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
<th>Do not know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sisters</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>2. Daughters</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>3. Mother</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>4. Other relatives (SPECIFY)</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>5. Close friends</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>9</td>
</tr>
</tbody>
</table>
SECTION E: KNOWLEDGE, ATTITUDES AND BELIEFS

E1. I am going to list some concerns women have reported about getting a mammogram. For each one, please tell me how concerned you are about this. To begin, does (READ EACH CONCERN) make you extremely concerned, somewhat concerned, a little concerned, or not at all concerned about getting a mammogram?

<table>
<thead>
<tr>
<th>Concern</th>
<th>Extremely Concerned</th>
<th>Somewhat Concerned</th>
<th>A little Concerned</th>
<th>Not at all Concerned</th>
<th>Do not Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. the cost of a mammogram</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>2. worry about the radiation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>3. the discomfort of the machine pressing your breast</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>4. fear of finding cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>9</td>
</tr>
</tbody>
</table>

E2. Would any of the concerns I have mentioned stop you from having a mammogram?

- No .............................................. 0
- Yes ............................................. 1
- (DO NOT READ) → Do not know .................... 9

E3. Would any other concerns stop you from having a mammogram?

- No .............................................. 0
- Yes (SPECIFY) .................................. 1
- (DO NOT READ) → Do not know .................... 9

E4. Would you say that getting a mammogram in the next year is (READ CHOICES)

- Very likely .................................... 1
- Somewhat likely ................................ 2
- Not very likely .................................. 3
- Not likely at all ................................ 4
- (DO NOT READ) → Do not know .................... 9
E5. How useful do you think mammograms are for early detection of breast cancer? Would you say ... (READ LIST)

Very useful ........................................ 1
Somewhat useful .................................. 2
Not very useful .................................... 3

(DO NOT READ) → Do not know ..................... 9

E6. For the next few statements, please tell me if you “strongly agree, agree, disagree or strongly disagree.” (READ STATEMENTS BELOW)

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>Do not Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. A women doesn’t need to have a mammogram unless she gets a breast problem</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. A woman can have breast cancer without having any symptoms</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Breast cancer can be cured if caught early enough</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Looking for breast cancer makes women worry</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Getting treated for breast cancer is often worse than the disease</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Having an operation for cancer can expose it to the air and cause it to spread</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

E7. Who do you think is more likely to get breast cancer - women under 65, women over 65, or age doesn’t make any difference?

Women younger than 65 ................................... 1
Women older than 65 ..................................... 2
Age does not make any difference ..................... 3

(DO NOT READ) → Do not know .......................... 9
E8. Out of 100 women, how many do you think will get breast cancer at some time during their lives? Would you say (READ CHOICES)

- <1 in 100 ........................................... 1
- 1-5 in 100 ........................................... 2
- 6-9 in 100 ........................................... 3
- 10-19 in 100 ........................................... 4
- 20 or more in 100 ........................................... 5

(DO NOT READ) → Do not know ........................................... 9

E9. Compared to most women, what do you think the chances are that you personally will get breast cancer some day? Do you think it is ... (READ CHOICES)

- Higher than most women ........................................... 1
- The same as most women ........................................... 2
- Lower than most women ........................................... 3

(DO NOT READ) → Do not know ........................................... 9

E10. Sometimes women worry about getting breast cancer. How about you? Would you say that you worry about getting breast cancer (READ CHOICES)

- A lot ........................................... 1
- Somewhat ........................................... 2
- A little ........................................... 3
- Not much at all ........................................... 4

(DO NOT READ) → Do not know ........................................... 9

E11. Where do you usually get information on health knowledge and health care? (READ CHOICES)

- Radio or TV ........................................... 1
- Newspaper ........................................... 2
- Magazine ........................................... 3
- Doctor ........................................... 4
- Family members ........................................... 5
- Friends or neighbors ........................................... 6
- Organization meeting ........................................... 7
- Other (SPECIFY) ........................................... 8
- No sources ........................................... 0

(DO NOT READ) → Do not know ........................................... 9
E12. Have you heard anything about breast examination through radio or television, or from family members, relatives or friends in the past year?

No ................................................. 0
Yes ............................................... 1

(DO NOT READ) → Not sure ......................... 9

E13. Have you attended an organization meeting or received educational materials on breast cancer in the past year?

No ..................................................... 0
Yes .................................................... 1

(DO NOT READ) → Not sure ......................... 9

E14. Did any of these things you heard or got make it more likely that you would get a breast examination?

No ..................................................... 0
Yes .................................................... 1

(DO NOT READ) → Do not know ....................... 9

SECTION F: PERSONAL FEELINGS AND HEALTH

F1. The following is a list of symptoms and complaints that people may sometimes have. If you had any of the symptoms or complaints in the past year, please tell me how many days it lasted during the most severe episode. During the past year, were you bothered by .

(READ EACH SYMPTOM AND ITS ANSWER CHOICES)

<table>
<thead>
<tr>
<th>No</th>
<th>Yes, lasting less than one week</th>
<th>Yes, lasting one to two weeks</th>
<th>Yes, lasting more than two weeks</th>
<th>Do not know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sad, blue, or “down in the dumps”</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Poor appetite</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Significant weight loss or weight gain</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Severe trouble falling asleep</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>Yes, lasting less than one week</td>
<td>Yes, lasting one to two weeks</td>
<td>Yes, lasting more than two weeks</td>
</tr>
<tr>
<td>---</td>
<td>----</td>
<td>---------------------------------</td>
<td>-------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>5. Sleeping too much</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Loss of energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Easily fatigued</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Feeling tired</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. Loss of your interest or pleasure in your usual activities</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10. Feeling guilty or down on yourself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11. Feeling worthless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12. Feeling lonely</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13. Irrational fear of physical illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14. Poor concentration</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15. Slowing of thinking</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16. Trouble making decisions</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17. Being unable to sit still and having to keep moving</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18. Feeling slowed down physically and having trouble moving</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19. Thoughts of ending your life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
SECTION G: OTHER

G1. What was your household income before taxes in the past year? (READ LIST)

<table>
<thead>
<tr>
<th>Income Range</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $5,000</td>
<td>1</td>
</tr>
<tr>
<td>$5,000 to $9,999</td>
<td>2</td>
</tr>
<tr>
<td>$10,000 to $14,999</td>
<td>3</td>
</tr>
<tr>
<td>$15,000 to $19,999</td>
<td>4</td>
</tr>
<tr>
<td>$20,000 to $24,999</td>
<td>5</td>
</tr>
<tr>
<td>$25,000 or more</td>
<td>6</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Refused .................................................. 9

G2. How many people living in your household were supported by that income during the past year? __ __ (persons)

G3. What is your religious preference?

<table>
<thead>
<tr>
<th>Preference</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>0</td>
</tr>
<tr>
<td>Protestant</td>
<td>1</td>
</tr>
<tr>
<td>Jewish</td>
<td>2</td>
</tr>
<tr>
<td>Catholic</td>
<td>3</td>
</tr>
<tr>
<td>Latter Day Saints</td>
<td>4</td>
</tr>
<tr>
<td>Other (specify)</td>
<td>5</td>
</tr>
</tbody>
</table>

G4. How often did you go to church, temple, or other religious services in the past year?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>0</td>
</tr>
<tr>
<td>Less than once a month</td>
<td>1</td>
</tr>
<tr>
<td>About once a month</td>
<td>2</td>
</tr>
<tr>
<td>About once every other week</td>
<td>3</td>
</tr>
<tr>
<td>Every week</td>
<td>4</td>
</tr>
</tbody>
</table>

(DO NOT READ) → Not sure .................................................. 9
AT THE END OF THE INTERVIEW

Thank you very much for your participating in this study. We appreciate you for your time and your help. As you may know, we will be mailing you a check of $25 for this interview.

FOR WOMEN IN INTERVENTION GROUP, SAY: According to our study plan, we will teach you some knowledge about women’s health. We will pay you an additional $15 for your time for the acceptance of the knowledge. IF LAY HEALTH EDUCATOR GOES WITH INTERVIEWER, ASK if we can teach you now? IF LAY HEALTH EDUCATOR IS NOT WITH INTERVIEWER, SAY, would you please let me know when you will be available for the acceptance of knowledge in the next few days? TAKE DOWN THE TIME SHE WILL BE AVAILABLE:

Time: __:__ (a.m./p.m.) Date: ___/___/____ (day/month/year).

FOR WOMEN IN CONTROL GROUP, SAY: According to our study plan, we will have another 30-40 minute interview with you next year. Again, we will pay you for that interview.

We look forward to seeing you again for the study. Please let me know if you have any questions.

IF RESPONDENT SAYS “YES,” ANSWER THE QUESTION. IF RESPONDENT SAYS “NO,” SAY “Good-bye.”
SECTION H: INTERVIEW REMARKS

H1. Respondent's overall cooperation was:

<table>
<thead>
<tr>
<th>Cooperation Level</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very good</td>
<td>1</td>
</tr>
<tr>
<td>Good</td>
<td>2</td>
</tr>
<tr>
<td>Fair</td>
<td>3</td>
</tr>
<tr>
<td>Poor</td>
<td>4</td>
</tr>
</tbody>
</table>

H2. The quality of information obtained from this interview is:

<table>
<thead>
<tr>
<th>Information Quality</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very reliable</td>
<td>1</td>
</tr>
<tr>
<td>Generally reliable</td>
<td>2</td>
</tr>
<tr>
<td>Questionable</td>
<td>3</td>
</tr>
<tr>
<td>Unsatisfactory</td>
<td>4</td>
</tr>
</tbody>
</table>

H3. The main reason for unsatisfactory or questionable quality of this interview was that the respondent:

<table>
<thead>
<tr>
<th>Reason for Unsatisfactory Quality</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was physically ill</td>
<td>1</td>
</tr>
<tr>
<td>Had poor hearing or speech</td>
<td>2</td>
</tr>
<tr>
<td>Did not understand or speak English well</td>
<td>3</td>
</tr>
<tr>
<td>Was insufficiently knowledgeable</td>
<td>4</td>
</tr>
<tr>
<td>Was confused or distracted by frequent interruptions</td>
<td>5</td>
</tr>
<tr>
<td>Was inhibited by others around her</td>
<td>6</td>
</tr>
<tr>
<td>Was bored or uninterested</td>
<td>7</td>
</tr>
<tr>
<td>Was upset or depressed</td>
<td>8</td>
</tr>
<tr>
<td>Was embarrassed by the subject matter</td>
<td>9</td>
</tr>
<tr>
<td>Was emotional unstable</td>
<td>10</td>
</tr>
<tr>
<td>Was hostile or uncooperative</td>
<td>11</td>
</tr>
<tr>
<td>Other (SPECIFY)</td>
<td>12</td>
</tr>
</tbody>
</table>

H4. The interview was conducted with the respondent while she was:

<table>
<thead>
<tr>
<th>Conduct Setting</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alone</td>
<td>1</td>
</tr>
<tr>
<td>With others present and listening (SPECIFY)</td>
<td>2</td>
</tr>
</tbody>
</table>
Mammograms are:
- **Lifesaving** - The earlier breast cancer is detected, the higher the rate of cure.
- **Effective** - A mammogram can detect a cancer as small as a pin head.
- **Fast** - It takes only 15 to 20 minutes for the examination.
- **Safe** - The radiation is less than you would get from dental x-rays.
- **Painless** - Most women feel little or no discomfort.
- **Affordable** - A mammogram every other year is covered by Medicare.

**Three “Shoulds” On Being Breast Cancer Smart**
- Have a mammogram every year.
- Have a yearly breast checkup by your doctor.
- See a doctor right away when you find a lump or other changes in your breast or when you have liquid seeping from your nipple.

**Six “Knowledges” On Mammography**
Mammography is an x-ray procedure that produces an image of the breast on film. The x-ray is called a mammogram.
Three “Highs” On Breast Cancer in African American Women

High Incidence
- Breast cancer is the most common cancer.
- Breast cancer comprises 32% of all new cancer cases.

High Death Rate
- Breast cancer is the leading cause of death from cancer among African American women.
- The mortality rate for African American women is higher than that for Caucasian women.
- There has not been a decline in the death rates in African American women as seen among Caucasian women in recent years.

High Risk Among Older Women
- African American women aged 50 and over are nine times more likely to develop breast cancer than women under 50. The likelihood among women age 65 and older is even higher.

Three “Highly” On Breast Cancer

Highly Curable
- If breast cancer is caught early, it is highly curable. A woman with early detected breast cancer can live almost as long as a woman without breast cancer.

Highly Recommended
- Regular breast examinations can detect breast cancer that has not caused any symptoms and, therefore, are highly recommended.
Increase Social Connections
Increase contact and communication with your social network will reduce your emotional problems. You can:

- Spend some time with your children or grandchildren.
- Participate in religious or community activities.
- Visit or call your relatives or close friends.
- Seek help from significant others.
- Go to a party or movie.

Plan Your Daily Activities
And Your Time

Creation of more purposeful activities in your life may give you confidence in yourself and in your abilities to live better. In doing so, you may:

- Plan out the things you would like to do or interest you the most.
- Schedule activities according to your pleasures and abilities.

Seek Help
From Health Professionals

- Call Dr. Lloyd Elam at 327-6774, in the afternoons, if you have questions about ways to get through emotional problems.
- Seek help from your doctor. If necessary, seek help from a psychiatrist.

What Do You Need To Remember?

- Do not expect to “snap out” of your emotional problems. Help yourself as much as you can.
- Do not crowd your schedule.
- Gradually take on a hobby or activity.
- You will feel better with time. You may feel so good through your efforts.

Meharry Medical College
Family & Preventive Medicine
1005 D.B. Todd, Jr. Blvd.
Nashville, TN 37208
What A Person May Feel Emotionally

A woman may face difficult problems during her lifetime, such as failed hopes and dreams, economic stress, divorce, separation and the death of loved ones. These situations may bring about emotional problems, even for a generally happy person, she may sometimes be in a bad mood.

She may feel:
- Sad, blue or "down in the dumps"
- Alone
- Hopeless or pessimistic
- Guilty, worthless or helpless
- Irrationally fearful of physical illness
- As if she wants to end her life

She may have:
- A loss of interest or pleasure in usual activities
- Decreased energy or become easily fatigued
- A loss or gain in appetite or weight
- Severe trouble falling asleep or sleeping too much
- Difficulty in concentrating, remembering or making decisions

What You Can Do If You Feel Emotionally Ill?

Adjust Your Negative Thoughts

When you feel bad emotionally, you focus on the negative sides and ignore the positive sides of things. Negative thoughts bring about emotional symptoms. It is important to realize that these negative thoughts are part of your emotional problems and typically do not accurately reflect your situation.

Emotional problems due to negative thoughts lessen as you:
- Accept your reality of life, and
- Reduce and overcome negative opinions of yourself.

Control Your Emotions

When you have emotional problems, you can:
- Have open discussions with significant others or friends to legitimize your problems.
- Participate in activities that absorb your interest and concentration to relieve tension. Some activities may include:

Walking the Dog  
Watching Birds  
Taking a Walk  
Exercising Regularly

Reading  
Cooking  
Cleaning  
Fishing
Meharry Medical College
Women’s Health Study

The Interviews’ Overview
An interview is a structured procedure with a scientific purpose by means of which the respondent, through a series of questions is induced to give verbal information. The personal interview, whether face-to-face or by telephone, is the commonest method of collecting data on exposure in epidemiological studies.
Four General Ways in Which the Performance of Interviews May Give Rise to Error

- Asking errors: Omitting questions or changing the wording of questions.

- Probing errors: Failing to probe when necessary, biased probing, irrelevant probing, inadequate probing.
Four General Ways in Which the Performance of Interviews May Give Rise to Error (cont)

- Recording errors: Recording something not said, not recording something said, incorrectly recording what was said.

- Flagrant cheating: Recording a response when a question is not asked or answered.
There are Two Types and Styles of Interviews

- Structured interview - is one in which all the interview's tasks, and even words, are set down on the interview questionnaire.

- Unstructured interview - A rapport is established with the study subject.
The Optimal Circumstances for an Interview Is Time and Place

- Time should be chosen to minimize, competing demands on the respondent.

- The easiest group to find at home at any time are those 65 years and older.

- Day of week is important in determining whether or not a respondent will be available.
The Optimal Circumstances for an Interview Is Time and Place (cont)

Research has found that weekday evening, Saturday any time & Sunday afternoons and evenings to be the best time for an interview.
Choosing the Location for the Interview

The location of the interview should be chosen so that it is away from distractions.

The interview should be able to sit facing the respondent, (so that the respondent cannot read the questionnaire), Ideally at a table so that it is easier for the interview to organize his or her papers.
Securing the Interview

- The interviewer should establish her identity by showing an official ID card from the institution conducting the research.

- The interviewer should adopt a positive manners, assuming that the interview will not be refused.
Questions Commonly Asked by the Respondent

- How did you happen to pick me?
- Who gave you my name/address?
- I really don’t know anything about this.
- What’s all this about anyway?
- What good will this do?
- What’s the catch?
- What else am I going to have to do?
- Why do you need my name?
Questions Commonly Asked by the Respondent (cont)

- How can I be sure that you won’t tell everyone else what I tell you?
- Why do you want to know that?
- What are you going to do with these answers anyway?
- When will I get paid?
Avoiding Refusals

If it appears that the respondent is going to refuse to be interviewed, the positive reasons for participation should be restated and any implied questions behind the refusal should be answered. As far as possible, a refusal should not be accepted until it is explicit.
Asking Questions and Obtaining Answers

- Questions should be read with correct intonation and emphasis.

- Questions should be read slowly, about two words a second.

- When a respondent mishears or misunderstands a question, it should be repeated in full.
Rules for Asking Questions in Highly Structured Interviews

- Read the questions exactly as they are worded in the questionnaire.
- Read each question slowly.
- Use correct intonation and emphasis
- Ask the questions in order they are presented in the questionnaire.
- Ask every question that applies to the respondent.
Rules for Asking Questions in Highly Structured Interviews (cont)

- Use response cards when provided.
- Repeat in full question that are misheard or misunderstood.
- Use only allowable probes.
- Read all linking or transitional statements exactly as they are printed.
- Do not add apologies or explanations for questions unless they are printed in the questionnaire.
Acceptable Non-directive Probes

- Repeat the question.
- The expectant pause.
- Repeat the reply.
- Neutral questions or comments (for clarification).
Rules for Recording Responses in Interviews

- Make sure that you understand each response.
- Make sure that each response is adequate.
- Do not answer for the respondent.
- Record all response during the interview
- Begin writing as soon as the respondent begins talking.
GUIDELINES ON THE PERSONAL INTERVIEW

Purposes Of Improving Interview Skills

1) Increasing the response rate
2) Obtaining accurate information
3) Obtaining complete data and reducing missing items

Issues For A Good Interview

1) Psychological Preparations

Perform an interview as if you have no knowledge of study group
Perform an interview as if you have no knowledge of study aims
Do not expect whether an interview will be difficult or not

2) Interview Time

• Tell a study subject time length for an interview to ensure sufficient time
• Convenient for study subjects
• Make an appointment if necessary

3) Appearance

• Clothes
• Manner
• Language
• Maherry badge

4) Introduction

• Introduction remarks as presented in the questionnaire
• Letter from the P.I. and Housing coordinator
• A little chat (weather, room, furniture,...) to create an easy conversational environment
5) Interview Place
   - Quiet and comfortable to study women
   - Separated from lay health educator or study helper
   - Sit face-to-face

6) Asking Questions
   - State the purpose to use a recorder (quality control) (Say “Our college asked me to record…”)
   - Read a question as it is in the questionnaire
   - In the order presented in the questionnaire
   - Ask all questions needed (skip when indicated)
   - Read all linking or transitional statements
   - Read slowly and clearly
   - Repeat a question, when necessary, in full
   - Use non-directive probing
   - No inductive questioning and directive probing
   - Provide question-by-question feedback

7) Recording Answers
   - Record only what has been said by study women
   - Record it correctly
   - Write a note when an answer is not clear

8) Editing
   - Check all answers immediately after an interview (missing, unclear,...)
   - Go back immediately to make up
INTERVIEWER’S EVALUATION OF LAY HEALTH EDUCATOR’S IMPLEMENTATION

Interviewer ____________ Lay Health Educator _______________ Subject ID# ______

1. The time spent for teaching on breast health was about _____ (minutes)

2. The time spent for teaching on emotional adjustment was about _____ (minutes)

3. The lay health educator’s overall teaching and role-play on breast health was:
   - Very good ........................................1
   - Good ..............................................2
   - Fair ................................................3
   - Poor ................................................4

4. The lay health educator’s overall teaching and role-play on emotional adjustment was:
   - Very good ........................................1
   - Good ..............................................2
   - Fair ................................................3
   - Poor ................................................4

5. Did the recipient of the education seem interested in the teaching on breast health?
   - Yes ................................................1
   - No ..................................................0
   - Not sure .........................................2

6. Did the recipient of the education seem interested in the teaching on emotional adjustment?
   - Yes ................................................1
   - No ..................................................0
   - Not sure .........................................2

7. Did the recipient ask any questions during teaching?
   - Yes ................................................1
   - No ..................................................0

8. Did the recipient seem to understand the teaching materials?
   - Yes ................................................1
   - No ..................................................0
   - Not sure .........................................2

9. Did the lay health educator leave the brochures at the recipient’s home after teaching?
   - Yes ................................................1
   - No ..................................................0
Intervention Study Tracking System
(Linked through ID#)
Dear Ms.

We are conducting a scientific study to increase breast screening among African-American women aged 65 and older. Ms. is one of the participants in our investigation. We are writing to you for your assistance in helping her get a breast examination.

Breast cancer is the most common cancer and the leading cause of cancer among African-American women. African-American women die from breast cancer more often than any other ethnic groups. However, many women would survive breast cancer if it was discovered early through regular breast examination and treated right away.

Studies have shown that support from one’s family and social network may be vital for some older women to get a breast screening. In our investigation, Ms. identified you as one of her significant others. Because you are special to her, your help will be very important for her getting a breast examination. There are a number of ways you can help her. You can advise her to get a breast examination by a physician or mammogram, drive her to a breast examination site, or provide emotional support. We have enclosed a brochure that provides you with detailed information on how you can help your loved one in improving her breast health.

If you could provide suggested help to Ms. , please sign the attached form and return it to us using the enclosed stamped envelope. Ms. will benefit from what you will do for her. She, we, and society will appreciate your help.

Sincerely,

Kangmin Zhu, M.D., Ph.D.
Principal Investigator
• Encourage her to get a breast examination.
• Drive her to a medical facility for an exam if she does not have transportation or is disabled.
• Give her a few dollars for an exam, if she needs it (a mammogram is covered every other year by Medicare. Clinical breast examinations can be done any time when she visits a health professional).

The Other Thing That May Be Important Is...

To help her maintain a good attitude. Because she lives without a spouse, she needs more concern and consolation. Your emotional support for her is indispensable. You may:

• Talk more with her on the telephone or in person and engage her in conversation.
• Encourage her participation in some activities that once gave her pleasure, such as hobbies, cultural or religious activities.
• Be patient and affectionate.

You Will Feel Gratified...

For what you will do for ___________. She and society will thank you.

For more information concerning breast cancer or screening, call the Cancer Information Service toll-free at 1-800-422-6237.

Meharry Medical College
1005 Dr. D.B. Todd, Jr. Blvd
Nashville, TN 37208
late stage breast cancer that is hard to cure, she and her significant others will suffer. However, if a significant person can help the woman in detecting an early-stage breast cancer, which is highly curable, then he/she can benefit from and be happy with what he/she has done for the woman.

The First Help You Can Give Her...

Is to provide her with information on breast health. An increase in knowledge of breast health may facilitate a woman’s breast screening behavior. You may convey the following information to her:

- Breast cancer is the most common cancer in African American women. It is more common among women aged 65 and older, than among those who are younger.

If breast cancer can be caught early, it is highly curable.

- Annual breast examinations (mammography and clinical breast examination) can detect breast cancer that has not even caused any symptoms.
- A mammogram can detect a cancer as small as a pin head, and is painless and safe.

The Second Thing You Can Do For Her...

Is to help her access a breast screening site. You may: