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| <b>13. ABSTRACT (Maximum 200 Words)</b><br><br>Mammography detects cancer an average of 1.7 years before a woman or her clinician can manually detect it. It is estimated that up to 60% of the women who have an inconclusive mammogram do not return for further medical evaluation, which could possibly detect cancer at an early and possible more treatable stage. Thus, despite the fact that early detection of breast cancer may be life-saving for some women, thousands of women who may be at risk do not follow through to receive a diagnosis. A convenience sample of 202 women from two urban medical centers was invited to participate in the study. All of the women had been notified of their abnormal mammograms within the past two years and instructed to return for further evaluation; 81 women returned for diagnostic evaluation and 121 did not return. Telephone interviews are being conducted to provide a greater degree of anonymity and disclosure. A review of the data suggests that women who have not returned for diagnostic follow-up reported receiving less health information concerning their mammograms and appear to have moderate to high levels of cancer fatalism, mild levels of depression, and a lower perception of cancer risk. An outcome of this study is the design of a culturally sensitive protocol to increase adherence to diagnostic evaluation. |                                                                 |                                                                |                                                                                   |  |
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\_\_\_\_\_ *Meris Brown Baker* 10/29/99  
PI - Signature Date

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## **INTRODUCTION:**

Mammography detects cancer an average of 1.7 years before a woman or her clinician can manually detect a tumor. Although early detection of a breast cancer lesion is a major influence on a woman's chances of survival, up to 60 percent of women with abnormal mammograms choose not to return for diagnostic follow-up. Follow-up procedures may include ultrasound, fine needle aspiration, a repeat clinical breast exam, a follow-up mammogram (additional views), or a breast biopsy. Previous research has not conducted a systematic investigation of the problem nor has there been a determination of the factors associated with a woman not obtaining diagnostic follow-up. Therefore, the major aims of this study are to determine the factors associated with a woman not obtaining diagnostic follow-up and to translate the research results into a protocol designed to increase the number of women who should return for diagnostic follow-up. The major outcome of this program of research is to increase early detection of breast cancer.

## **BODY:**

Achieving academic, professional and logistical milestones have been the focus of this first year of the research training grant. I have successfully completed Tasks 1 and 2 of the Statement of Work and I am currently in the process of completing Task Three.

The major academic achievement was successfully passing the Preliminary Oral Examination that was scheduled for March of this year. This examination satisfies certain requirements stipulated by both the School of Nursing and the Graduate Board Office of the Johns Hopkins University.

A pilot study, which investigated African American women's perceptions and experiences obtaining breast and cervical cancer screening services, was presented at two national conferences. Poster presentations were given at the Fifth National Conference on Cancer Nursing Research in Newport Beach, California and the Oncology Nursing Society, 24<sup>th</sup> Annual Congress, in Atlanta, Georgia. In addition, a "work in progress" abstract on the personal reasons given for obtaining or not obtaining diagnostic follow-up was submitted this Fall to the 11<sup>th</sup> International Conference on Cancer Nursing in Oslo, Norway.

A great deal of preparation and startup time was necessary before this study could begin. The relatively small number of women with abnormal mammograms necessitated obtaining Institutional Review Board (IRB) approval at two locations. Although the original protocol proposed the Washington Hospital Center in Washington, D.C. as a second data collection site, the facility was unable to accommodate this study. Consequently, the search for another institution willing to grant IRB approval to a doctoral student, not affiliated with that facility, delayed the commencement of data collection. The University of Maryland Medical Center was finally identified as the second site and IRB approval was eventually obtained both there and at the Johns Hopkins University Hospital. The standardization of procedures between the two institutions caused a time delay in initiating the study. Johns Hopkins University approved an approach in which women who refused participation in the study, decline by leaving a message at a toll-free phone number. This is consistent with the original protocol. In contrast, the University of Maryland approved that those who wished to decline participation in the study mail a pre-paid postcard to the Principal Investigator.

In addition, the proposal was expanded to include depression as a possible determinant of diagnostic follow-up and another instrument was substituted to assess the interaction between the woman and her health care provider. Consequently, the Beck Depression Inventory and the Breast Cancer Screening Satisfaction Survey were added to the protocol. Participant recruitment was problematic due to the large number of women in the low-income East Baltimore Maryland area who were reluctant to participate in medical related research. Subject reimbursement was increased from \$5 to \$10 food gift certificates to encourage participation and the consent form was amended. A revised protocol was submitted to the U.S. Army Medical Research and Materiel command.

Data Collection procedures were installed and the computerized tracking system records from the respective radiology departments were obtained. Advance letters were addressed and mailed to 202 women in September of this year; 81 women who returned for diagnostic evaluation and 121 women who did not return. Telephone interviews are being conducted because it is believed to provide a greater degree of anonymity and disclosure for those women who may be hesitant to discuss this issue. Currently, 10 women have been recruited into the study. A review of the data suggests that women, who have not returned for diagnostic follow-up, reported receiving less health information concerning their mammograms and appear to have moderate to high levels of cancer fatalism, mild levels of depression, and a lower perception of cancer risk. A major outcome of this study is to identify factors related to the decision of whether to obtain evaluative care following an abnormal mammogram so that this information can be used to design an innovative and culturally sensitive protocol to increase adherence to diagnostic evaluation.

## **KEY RESEARCH ACCOMPLISHMENTS:**

Trends indicate that women who have not returned for follow-up:

- Did not perceive themselves to be at risk for cancer
- Reported receiving less health information concerning their mammogram
- Had moderate to high levels of cancer fatalism
- Had mild levels of depression

## **REPORTABLE OUTCOMES:**

### **Poster Presentations**

Voices From Women on the Decision to Seek Care after an Abnormal Mammogram. Bakos, A. Abstract submitted to the 11<sup>th</sup> International Conference on Cancer Nursing. Oslo, Norway. July 30-August 3, 2000.

Cancer Equals Death: A Phenomenological Investigation of African American Women's Perceptions of Cancer Screening Services. Bakos, A. Oncology Nursing Society, 24<sup>th</sup> Annual Congress. Atlanta, GA. April 28-May 1, 1999.

Cancer Equals Death: A Phenomenological Investigation of African American Women's Perceptions of Cancer Screening Services. Bakos, A. Fifth National Conference on Cancer Nursing Research. Newport Beach, CA. February 10-13, 1999.

### **Abstract**

Bakos, A.B. (1999). Cancer equals death: A phenomenological investigation of African American women's perceptions of cancer screening services. Oncology Nursing Forum Abstract No., 170, 396.

### **Recognition**

Semifinalist in the 1999 Oncology Nursing Society/Shering Excellence in Cancer Nursing Research Award

### **Research Opportunity**

Applied for the National Cancer Institute Cancer Prevention Fellowship Program for the year 2000

## VOICES FROM WOMEN ON THE DECISION TO SEEK CARE AFTER AN ABNORMAL MAMMOGRAM

Alexis Brown Bakos, MSN, RN,C

The purpose of this study is to learn why some women with abnormal mammograms do not return for evaluative follow-up care. An estimated 60% of the women who have an abnormal mammogram do not return for further medical evaluation. A convenience sample of 202 women from two urban hospitals was invited to participate in the study. All of the women had been notified of their abnormal screening mammograms within the past two years and instructed to return for further evaluation; 81 women returned for diagnostic evaluation and 121 did not return. Telephone interviews are being conducted to provide a greater degree of anonymity and disclosure as each woman is asked why she decided to return or not return for follow-up care. Significant statements will be extracted from the interviews, coded and then grouped into categories. Manifest content analysis will achieve a fundamental level of understanding of relevant factors. Descriptive statistics will be used for sample and category analysis. The category system will be tested by determining its interrater reliability. Content validity will be assessed by returning to the original narrative data and relating it to the Interaction Model of Client Health Behavior conceptual framework. A major outcome of this study is to identify factors related to the decision whether to obtain evaluative care following an abnormal mammogram so that this information can be used to design an innovative and culturally sensitive protocol to increase adherence to diagnostic evaluation.

## CANCER EQUALS DEATH: A PHENOMENOLOGICAL INVESTIGATION OF AFRICAN AMERICAN WOMEN'S PERCEPTIONS OF CANCER SCREENING SERVICES.

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African American women (AAW) are reluctant to participate in secondary prevention practices such as breast and cervical cancer screening. The majority of research has focused on the barriers AAW experience obtaining an initial cancer screening test. The purpose of this preliminary phenomenological study was to gain an understanding of the experience of elderly AAW, who received gynecologic cancer screening services, and to explore their views about how their experience would influence their decision to participate in these services in the future. The research question was: "What is the lived experience of elderly AAW receiving breast and cervical cancer screening services?" The purposive sample consisted of six AAW, ages 60 years or older, who received a Pap smear and/or screening mammogram at the recommendation of a family member or their physician. The women were interviewed in their homes to explore the experience of obtaining cancer screening services. Responses were recorded verbatim, then transcribed. Existential-phenomenology was the philosophical framework for this study and the descriptive phenomenological method of Colaizzi was used to analyze the data. Significant statements were extracted from the interviews, coded and then grouped into cluster themes that described the essence of the experience. These themes were integrated and synthesized into statements that were fundamental to the phenomenon, and finally validated by the women themselves.

Two themes emerged from the analysis: 1) cancer equals death; and 2) distrust of medical providers. Fatalistic views were expressed concerning cancer in general. Participants expressed a belief that they would consider cancer a death sentence if confronted with the diagnosis. This belief was supported by the shared experiential reality of having a close family member or friend die quickly and painfully from cancer. Surgical treatment for breast cancer only hastened the spread of the disease according to the women. Participants also described perceptions of a health care delivery system fraught with difficulty and collusion. Medical practitioners were viewed as disrespectful toward patients, prejudicial, paternalistic, and lacking professionalism. This in turn fostered a distrust of the care and treatment they provided. Although participants had received breast and cervical cancer screening services in the past, most expressed an unwillingness to use cancer early detection measures in the future due to cancer fatalism and mistrust of medical professionals. The results of this study underscore the need for clinicians to design innovative ways to dispel ingrained cancer myths as well as provide culturally sensitive, patient-centered health care. Cancer screening initiatives targeted to minority women that do not address these concerns will fall short in promoting a climate in which AAW both receive initial screenings and return annually for early detection procedures. Future research should investigate the extent of elderly AAW not returning for annual cancer screening, and develop and test a culturally sensitive intervention strategy designed to increase the number of AAW who adhere to screening guidelines.