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13. ABSTRACT (Maximum 200 Words) An exploratory study was conducted in which 25 African-American female breast cancer survivors were interviewed. The purpose of this exploratory study was to identify barriers to early detection of breast cancer among African-American females over the age of 55. It was designed to result in the articulation of hypotheses for further study. The literature review confirmed that there are disparities in rates of early diagnosis of breast cancer among African-American women between the ages of 55 and 70. Based on the findings from the literature review, a semi-structured interview protocol was developed to explore beliefs and practices around breast cancer and breast cancer screening among a small sample of up to 25 African-American breast cancer survivors over the age of 55. For most of them, breast cancer was detected and treated during its early stage. There was a sense among them that breast cancer was not something that the women expected to encounter, even for those with family histories of the disease. Emerging from these 25 interviews were several interesting issues for future research, one of which was relating to spirituality.				
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Barriers to Early Detection of Breast Cancer among African-American Females Over Age 55

Final Report

INTRODUCTION

This exploratory study to identify barriers to early detection of breast cancer among African-American females over the age of 55 was designed to result in the articulation of hypotheses for further study. Work on this project has been completed and the funding period has expired. This document represents the final report of activities and outcomes for this project.

BODY

The following is a list of specific tasks in the project workplan. For each task, a short description of the accomplishments provided. Additional documentation is provided in the form of appendices where appropriate.

Task 1. Conducting an extensive literature review - An extensive review of the literature was conducted at the beginning of the project. The summary report of the literature review is included as Appendix A.

Task 2. Developing a study protocol - The protocol for the study was developed and approved by the local IRB (which was granted FWA), as well as by the Department of Defense review process. The study protocol is included as Appendix B.

Task 3. Outlining a sampling strategy - The sampling strategy was developed and is described in the study protocol, Appendix B.

Task 4. Scheduling preliminary interviews with potential subject to review study format and discuss informed consent procedures - Each study participant had a preliminary interview during which time the study was explained and the informed consent process was reviewed. This was followed by a confirmation call to arrange the interview. Each participant signed two copies of the consent form, retaining one for their own records and the other was filed in a locked filing cabinet in the Principal Investigator's office.

Task 5. Conducting up to 25 in-dept interviews - Twenty-five in-depth interviews were conducted with African-American female breast cancer survivors who were over the age of 55 at the time of the interview.

Task 6. Reviewing and coding transcripts of interviews - All interviews were tape recorded. Additionally, the interviewer took notes during the interviews. All tapes were transcribed. All transcripts and notes were coded for analysis

Task 7. Conducting data analysis – Content analysis was completed on all transcripts and notes. Findings are summarized in Appendices C (Power Point Presentation) and D (Draft Manuscript)

Task 8. Interpretation of data – Data interpretation was accomplished and is summarized in Appendices C (Power Point Presentation) and D (Draft Manuscript)

Task 9. Preparation of manuscript for submission to peer review journal – A draft manuscript has been prepared (Appendix D). It will be submitted to the Health and Social Work journal.

Task 10. Preparation of PowerPoint presentation of findings of study – The Power Point Presentation summarizing the major findings of the study is included as Appendix C.

Task 11. Preparation of final report, including recommendation future study – This document represents the final report for the project.

KEY RESEARCH ACCOMPLISHMENTS

- The research team has a better understanding of the various experiences of the subjects relating to the detection and treatment process for their encounters with breast cancer.
- The team has identified limitations of this study and made recommendations for future study.
- A proposal has been developed in draft form for submission for funding of a follow-up project to this study. The proposal will be a part of a larger, multi-project application to the National Institutes of Health.

REPORTABLE OUTCOMES

- A proposal has been developed in draft form for submission for funding of a follow-up project to this study. The proposal will be a part of a larger, multi-project application to the National Institutes of Health.
- A draft manuscript has been prepared for submission to the Health and Social Work journal.
- A presentation format has been developed and submitted to a topic group for the National Association of Black Social Workers for consideration for the 2006 Annual Meeting.

CONCLUSIONS

General conclusions based on findings are presented in the draft manuscript (Appendix D)

There are two recommendations for future study. They are both based on limitations identified during this investigation. One limitation of this study was the small sample. Although these women had a variety of stories to tell relating to their diagnosis and treatment of breast cancer, family values and practices about health, and screening habits prior to the diagnosis, the findings were not conclusive as new ideas continued to emerge as the interviews progressed. The investigator determined that an additional 25 interviews were recommended to identify specific nuances of training and outreach programs that may be especially useful in encouraging practices that would result in early detection for breast cancer in African-American females. A second limitation was related to the sampling strategy. Because a modified snowball sampling strategy was used, the group of subjects was somewhat homogeneous in many demographic factors. The investigator recommended that any follow-up study should add a quota sampling process to the methodology to assure that future samples are heterogeneous at least in terms of marital status, living arrangement, socio-economic status, family history of breast cancer, family history of cancer, stage of breast cancer at diagnosis, religious beliefs, health coverage, and educational

Annual Report Appendix A

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Barriers to Early Detection of Breast Cancer Among African-American Females Over Age 55

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Annual Report (9/03-9/04) Appendix A

Summary of Literature Reviewed

SUMMARY OF LITERATURE REVIEWED

INTRODUCTION

In 2001, the most common cancer among African American women was breast cancer (31%). Breast cancer is the second leading cause of death among African American women, exceeded only by lung cancer. In 2001, approximately 19,300 new cases are expected among African American women, while 5,800 are expected to die of breast cancer (American Cancer Society, 2000). Most significantly, African American women have higher mortality rates from breast cancer than any other group of Americans. The mortality rate for African American women is 35.7%; white women is 27.3%; Hispanic women is 16.8% (National Vital Statistics System, 1998)

INCIDENCE OF BREAST CANCER

Breast cancer is the most common form of cancer among women in the United States. The incidence of breast cancer has been rising over the past two decades, while mortality has remained stable. Although much of the increase is attributable to increased screening by mammography and physical examination, screening alone does not explain this increase. The age-adjusted incidence of invasive breast cancer indicates in descending order that white, African-American and Hawaiian women have the highest rates of breast cancer. In situ breast cancer occurs at much lower rates than invasive breast cancer, but has similar racial/ethnic patterns as does the invasive cancers (SEER, 2001).

Age specific incidence rates for invasive breast cancer present similar ethnic patterns. Among women aged 30 – 54 years, however, whites and Hawaiian women are similar, followed by African American women. Among women aged 55-69 years and 70 years and older, age specific incidence rates follow the same ethnic patterns as for those aged 30-54 years. In situ breast cancer incidence among women aged 30-54 years and 70 years and older is highest among white non-Hispanic women, followed by Japanese women, and white (total) women. At ages 55-69 years, in situ breast cancer is highest among white women, followed by Japanese women and African American women (SEER, 2001).

Inflammatory breast cancer is a clinical and pathologic entity characterized by rapid disease progression and poor diagnosis. Although it accounts for less than 5% of all invasive cases of breast cancer diagnosed in the US each year, it is one of the most lethal types of breast cancer with incidence higher in African American women than in white women. Increased risk of inflammatory breast cancer has been linked to high body mass (National Cancer Institute, 2001).

Important risk factors for female breast cancer include early age at onset of menarche, late age at onset of menopause, first full-term pregnancy after age 30, a history of pre-menopausal breast cancer for mother and a sister, and a personal history of breast cancer or of benign proliferative breast disease. Obesity, nulliparity and urban residence also have been shown to be associated with increased risk. From a preventative perspective, physical activity is suggested as a mitigating factor for breast cancer incidence (SEER, 2001).

Select risk factors are particularly relevant for African American women. By 1998, 64% of African American women were overweight and 32% were characterized as obese (American Cancer Society, 2000). Data from the 1998 Behavioral Risk Factor Surveillance System indicate that 40% of African American women reported no leisure-time physical activity (Surgeon General, 1996). Yet, findings suggest that strenuous physical activity in early adulthood is associated with reduced risk of breast cancer in African American women (Adams-Campbell, et al., 2001).

DISPARITY IN MORTALITY RATE

Notwithstanding the national stabilization rates of mortality from breast cancer, cancer mortality among African American women is approximately 28% higher than white women (American Cancer Society, 2000). Moreover, African American women who are diagnosed with breast cancer are less likely than white women to survive five years after diagnosis, the rate among African American women is 71%, compared to 86% among white women (Ries, et al., 2000).

In the age groups of 30-54 years and 55-69 years, African American women have the highest mortality rates. In the 70 years and older age group, the mortality rate for white women exceeds that for African American women (SEER, 2001).

Multiple studies have established the fact that the differential breast cancer mortality rate between African American and white women is due to the fact that a larger percentage of African American breast cancers are diagnosed at later, less treatable stages (SEER, 2001; Baquet & Comiskey, 2000; Joslyn & West, 2000; Chu, et al., 2000; Aziz, et al., 1999; Phillips, et al., 2001; Polednak, 2000.)

It is crucial to identify and understand the factors that are associated with late diagnosis breast cancer for African American women. The factors are complex and interrelated. The following studies indicate that the health care system, economic access and its practices as well as demographic factors are associated and interrelated with late-stage breast cancer diagnosis:

Role of the Health Care System

Economic access to health care, insurance is associated with late stage diagnosis. Studies indicate that persons lacking health insurance and persons insured by Medicaid are more likely diagnosed with late stage breast cancer (Rimer, et al., 1996; Roetzheim, et al., 1999). Since African American women are more likely to not have insurance or to rely on Medicaid entirely or as part of their insurance package, insurance status is one factor associated with their late stage diagnosis.

However, racial differences in late stage diagnosis are not explained entirely by insurance coverage (Roetzheim, et al., 1999). When type of coverage is held constant as it was in the Military Health System study (Bibb, 2001) and in the Josephine Ford Cancer Center managed care study (Yood et al., 1999), African American women were still diagnosed at later stages than

were white women. In the Military Health System Study, the African American women were of lower SES than their white counterparts.

An examination of health care system practices, per se, reveals other factors associated with late stage diagnosis. Studies have explored the role of physician recommendation for mammography, a precursor strongly associated with mammography use. A study of single, older women, 65 years and older residing in Nashville, TN housing projects showed that access to regular medical care and receiving a physician's recommendation are strongly associated with mammography among these women (Zhu et al., 2000).

O'Malley's et al. (2001) study of a rural older women found that recommendation for mammography was 10% higher for white women than African American women. Further, mammography was more frequent among women who had a regular physician and health insurance. Recommendation was less frequent among women who were more vulnerable and older, and had low formal education and low income. Although African American women received fewer recommendations for mammography than white women, in this study, racial differences disappeared when SES was controlled.

Another study produced finer grain information on the impact of type of health care practitioner providing the recommendation. It was found that low income African American women who were referred for a mammography by a physician's assistant or nurse practitioner were less likely to miss their appointments than women referred by a physician (Crump, 2000).

In lieu of regular mammography screening, it appears that African Americans particularly those of low SES have more incidental breast self-examination-discovered cancers than do white women (Bibb, 2001; Tessaro et al., 1994). This finding, leads Bibb (2000) to conclude that the most significant predictors of late-stage diagnosis were means of discovery and the length of time between discovery and diagnosis. Generally, breast self-examination- discovered cancers are in later stages than those discovered through mammography. African American women who avoid the medical system or for whom the medical system fails to recommend screening are more likely to be diagnosed at later, often untreatable stages of breast cancer.

In addition to mammography recommendation, it is suggested that there is a difference in actual treatment of cancer for African American women (Chu et al., 2000). Breen's et al. (1999) study results found that thirty-six percent of the patients with late stage disease did not receive minimum expected therapy compared to four percent of the patients with early stage disease. Older women and women with no usual source of care were significantly less likely to receive minimum expected therapy. Overall, 21% of African American women did not receive minimum expected therapy compared to 15% of white women. Furthermore, minorities with cancer often suffer more pain due to under medication. Nearly 62% of patients at institutions serving predominately African American patients were not prescribed adequate analgesics (Ross, 2000).

Focusing on the one-to one relationships between health care personnel and African American women, positive attitudes of health care personnel are important to patients. Gates's et al. (2001) ethnographic study indicates that professional caring supports women to seek breast cancer

diagnosis and treatment, whereas non caring related to a 'wait and see' attitude of health care providers encourages women to delay early diagnosis.

The health care system is not color blind. African American women often experience the health care system and its personnel as discriminatory, whether or not the motives are racially driven or are clouded by age and gender bias, low income, lack of or low reimbursement insurance coverage (Clark, 2001). Differentials in frequencies of mammography recommendations and treatment regimes between white and African American women are viewed as manifestations of health care personnel's negative attitudes and beliefs about African American women. These issues create a lack of trust of the medical system to do what is best for African Americans and their families (Frederick Schneiders Research, 1999). Given this context, it is not difficult to understand African American women's reluctance to take full advantage of the health care system, especially in availing themselves of early diagnostic procedures and follow-up on physician recommendations. Although not documented experimentally, it is likely that the African American women's wary perception of the health care system is an important factor associated with their late stage diagnosis of breast cancer.

DEMOGRAPHIC FACTORS

SES

As suggested by many studies, SES is a critical factor in late stage diagnosis. Late-stage breast cancer is more likely to be diagnosed in African American women of low SES (Bibb, 2000; Crump et al., 2000). Correspondingly, breast cancer mortality is higher for women of lower SES (Baquet & Commiskey, 2000). Since African American women are likely to have incomes below poverty level (Haynes & Smedley, 1999), the association of low income with late-stage diagnosis and high mortality rates for breast cancer is particularly relevant for this population. Although, it is suggested that racial disparities in breast cancer are smaller than when SES is examined alone, disparities still exist (Baquet & Commiskey, 2000).

Educational Attainment

Lower educational attainment is associated with late-stage diagnosis (Rimer et al., 1996; O'Malley et al., 2001), but studies have not found educational status to be independent predictive factor of late stage diagnosis. Rather, studies that examined educational attainment combined it with other factors such as income. Nonetheless, since African American women have lower educational attainment levels than do white women, the association of low education and late-stage diagnosis is relevant to African American women.

Educational attainment or status is not to be confused with education about breast cancer. These are two different factors. One cannot assume that higher educational status incorporates knowledge about breast cancer. Nothing in the literature supports this assumption.

However, lack of education about breast cancer is associated with late diagnosis in a number of studies, whereas education about breast cancer appears to be factor and strategy that increases mammography use. (See Sections about Cultural Context and Programs for Early diagnosis)

Residence

There is an interaction between race and residence in late stage diagnosis. Rural African American women are diagnosed much later than are urban African American women or white women of either residence (Amey et al., 1997). In California, early diagnosis of breast carcinomas differed markedly not only by age, ethnicity, diagnosis year, but county of residence, as well (Menck & Mills, 2001).

Health care physical access in rural areas in most instances is more problematic than in urban areas. General access problems may exacerbate the factors of health insurance, physician practices and perceived discrimination that lead to late diagnosis.

Health care system issues and demographic factors are associated with late stage diagnosis of breast cancer of African American women and contribute to the disparity between them and white women. Many of these factors are interrelated. In some studies, contradictions emerge. However, most studies indicate that despite the impact of these demographic and health system focused factors, unexplained factors remain within the African American population that also contribute to late stage diagnosis for breast cancer.

CULTURAL CONTEXT

Breast health care and breast cancer are interwoven with beliefs, attitudes and health care practices that are part of a cultural context. An exploration of these beliefs and attitudes provide a rich informational source to understand late stage diagnosis of breast cancer among African American women. In particular, the few available qualitative studies yield significant insights.

A study of a general population of African American and white women found significant differences on all of the health beliefs about cancer. African American women were more likely to believe in chance, or to believe in powerful others for their health. Moreover, African American women underplayed their susceptibility to cancer, doubted the value of early diagnosis and tended to regard the diagnosis of cancer as inevitably leading to death. Although higher education status mediated these beliefs for white women, it did not for African American women (Barroso et al., 2000).

Phillip's et al. (1999) qualitative study sought to understand the beliefs, practices and attitudes related to breast cancer and breast cancer screening among low-income and middle-income African American women. Women from three employment groups comprised the focus group sample. Findings indicate that when cancer was discussed, the primary feeling in all groups was fear. Fear was a primary reason not to engage in screening. All participants stressed that breast cancer is seldom discussed within the community. Teachers felt that the secrecy may lead to African American women thinking breast cancer to be a white women's disease. Unemployed and service workers emphasized the role of violence in causing breast cancer, whereas teachers identified sex and injury as causal.

McDonald et al. (1999) studied the perceptions and knowledge about breast cancer among African American women residing in public housing. They found that breast cancer knowledge was poor. Women did not perceive themselves or a particular racial or economic group to be more susceptible to breast cancer, nor did they perceive breast cancer as a fatal disease. The

women, by and large, endorsed the benefits of mammography and denied the relevance of commonly cited barriers to breast cancer screening. Yet, by using a different methodological approach, it was found that these women did indeed, perceive barriers to clinical breast examinations.

The study on single older women in Tennessee housing projects indicates that education on breast cancer, having living children and being involved with social activities were associated with use of mammography (Zhu et al., 2000). So, although higher educational status may not mediate erroneous beliefs about cancer (Barroso, et al., 2000), education specifically about cancer may be predictive of increased mammography use.

A study by Crump et al. (2000) explored the factors related to noncompliance with screening mammogram appointments among low-income African American women. It found that women who missed appointments did so because of embarrassment, lack of symptoms, and forgetfulness.

In Mayo's et al. (2001) study of rural elderly women, fatalism was positively associated with increased age and decreased educational level. More significantly, fatalism was associated with noncompliance with mammography screening among African American women.

Through a qualitative study eliciting social and cultural themes related to breast cancer screening, it was found that for older African American women: other health concerns are of more concern than cancer, age is generally not recognized as a risk factor, fear of finding breast cancer and its social consequences are barriers to mammography, they tend to rely on breast self-exam rather than mammography, cost is more an issue of competing priorities than cost per se, the tradition is to go to the doctor for a problem, not prevention, and women in their own social networks are important sources of social support for health concerns (Tessaro et al., 1994). This qualitative study enables income to be viewed through a different lens. That is, it raises the question that in some situations, it may not be low income that drives decision about mammography use, but instead, the value one places on mammography within the larger issues of how to spend one's income.

Gates's et al. (2001) ethnographic study sought to understand the impact of caring for others on decision to delay diagnosis and maintain continuing treatment. Would time commitments to caring for other people delay diagnosis and treatment? The study indicated that caring for others is meaningful and promoting continued commitment to diagnosis and treatment, caring from others both generic and professional as supportive for the women to continue treatment, and non caring related to the "wait and see" attitude of healthcare providers and of women delaying early treatment, as the reason for delay in seeking care.

Phillips' et al. (2001) phenomenological study of low-and middle-income women sought to describe the experience and meaning of breast cancer screening for African American women. The women spoke of their desire for a holistic approach to health that did not separate the breast from the rest of the body. This desire is indicated in the theme of minding the body, self and spirit, along with themes of relationships.

Critical themes emerge from exploring the impact on mammography use of African American women's beliefs and education about breast cancer. Although formal educational level appears not to influence beliefs and knowledge about breast cancer, specific education about breast cancer appears to be associated with higher mammography use. The second theme is that African American women hold beliefs and attitudes about breast cancer that are counter-productive to early and routine screening by mammography. These beliefs may be manifestations of their lack of knowledge about breast cancer. Third, the theme of relationships with family and others, as well as being needed and depended upon by their significant others appear to be linked positively to mammography use.

IMPACT OF AGE

The demographic and health system factors associated with late-stage diagnosis are more pronounced with age. African American women are more likely to have lower incomes, no insurance or Medicaid insurance, have lower educational status, have less frequent referrals for mammography from physicians and rely more on self-examination than mammography than either the younger African American or the older white cohorts (O'Malley, et al., 2001; Menck & Mills, 2001; Ackerman, et al., 1992; Tessaro, et al., 1994). Further, they are more likely than other cohorts of women to hold belief patterns in opposition to early diagnosis (Mayo et al., 2001). Older African American women are at great risk for late diagnosis.

PROGRAMS TO FACILITATE EARLY DIAGNOSIS

Several initiatives have been undertaken to increase mammography use by African American women. Recognizing the importance of natural networks in the African American communities, two projects sought to use these networks for education about breast cancer and the importance of early diagnosis through mammography. A California study (Derose, et al., 2000) recruited 50 – 80 year old African American, Latino and white women to participate in a mammography promotion program through their churches. It was found that an extended resource intensive period of relationship-building and community-based activities were necessary to conduct church-based programs effectively, particularly among older and ethnically diverse urban populations.

A creative California study sought to educate African American women about the importance of early detection of breast cancer through an educational program directed to their natural network, African American cosmetologists. The expectation was that the cosmetologists would inform and their clients about the benefits of routine screening and early diagnosis of breast cancer. Both cosmetologists and their clients demonstrated that despite their hearing the message from other sources, a substantial proportion had never realized breast cancer's high morbidity and mortality within their own community (Sadler, et al., 2000).

Recognizing the importance of income, access to health care systems and breast cancer education, a study reported in Boston sought to increase mammography rates among inner city non-Caucasian women 50 years and older by removing the barriers associated with cost and securing mammogram appointments. A peer delivered intervention, which consisted of a brief motivational interview, mammography referral at the time of the primary care visit and the

scheduling of a next-day, free mammography appointment. The results were that 60% had kept the mammography appointment of which 69% were first time users. Of those who did not keep the appointment, 77% requested a "second chance" (Bernstein, et al., 2000). Although this study did not evaluate the importance of the peer motivational interview, this is a promising factor for later studies.

The NCI "Public Health Approaches to Breast and Cervical Cancer" initiative sought to change internal health care access mechanisms and provide outreach and education as ways of encouraging mammography use. Funding in North Carolina was instituted to improve the use of breast and cervical cancer screening among low-income, predominantly African American women age 40 and older. Strategies implemented included public health clinic in reach strategies (chart reminders, exam room prompts, in-service meetings, and patient-directed literature) and community outreach strategies (educational sessions, literature distribution, community events, media and church programs). In the city with the intervention strategies, the use of mammography increased from 31% to 56%. In the non-intervention city, increase was not significant. This study indicates that a multifaceted intervention can improve screening rates for breast cancer in a low-income population (Paskett, et al., 1999).

A study methodology of informing older women of their mammography benefits via a mailing proved successful. This study sought to publicize the Medicare subsidized biennial mammogram benefit. The intervention was a targeted mailing informing older women about the benefit. Mammogram use increased significantly among minority women in the experimental group. In fact, African American women were twice as likely to undergo screening relative to the women in the control group (Fox, et al., 2001).

On the other hand, there was minimal effect of patient reminders on the use of screening mammography in an urban health department primary care setting. Participants were predominantly African American, two-thirds were over the age of 50 and all had minimal health coverage. Letters directed to reminding women to contact either their primary care physician or the clinic directly to schedule a mammogram, had no greater impact than not receiving any letter at all (Simon, et al., 2001). Unlike the Medicare study that provided information about the low-cost Medicare benefit, this intervention was only a reminder of need for appointment.

Recognizing that African American women depend on breast self-examination, the Howard University College of Nursing, sought to reinforce self-examination and reinforce that it is an important component in an educational program. Their study targeted inner city elderly African American populations. The objectives of the study were to determine the breast cancer knowledge of subjects, their level of confidence when performing self-examination, and if individual instruction, one-to-one practice and feedback on performance made a difference in screening practices. They found that more intensive interventions sustain breast examination self-efficacy. No other results were reported (Adderley-Kelly & Green, 1997).

These programs indicate that education, particularly through natural networks and peers, removing barriers of cost and access to health care and revisions in the operations of health care sites can increase mammography use and other screening use by low-income African Americans, and in particular, the older cohort.

References

Ackerman, S.P., Brackbill, R.M. Bewerse B.A., Cheal, N.E., Sanderson, L.M. (1992). "Cancer screening behaviors among U.S. women: breast cancer, 1987-1989, and cervical cancer, 1988-1989." Morbidity and Mortality Weekly Report CDC Surveillance Summary, Apr 24; 41(2): 17-25.

Adams-Campbell LL, Rosenberg L., Rao RS, Palmer JR. (2001). "Strenuous physical activity and breast cancer risk in African American women." Journal of the National Medical Association Jul-Aug; 93(7-8): 267-75.

Adderley-Kelly, B.& Green, P. (1997). "Breast cancer education, self-efficacy, and screening in older African American women." Journal of National Black Nurses Association Spring-Summer; 9(1): 45-57.

American Cancer Society. (2000). Cancer facts and figures for African Americans 2000-2001. Atlanta, GA, American Cancer Society.

Amey CH, Miller MK, Albrecht SL. (1997). "The role of race and residence in determining stage at diagnosis of breast cancer." Journal of Rural Health Spring;13(2): 99-108.

Aziz H, Hussain, F, Sohn C, Mediavillo R, Saitta A, Hussain A, Brandys M, Homel P, Rotman M. (1999). "Early onset of breast carcinoma in African American women with poor prognostic factors." American Journal of Clinical Oncology Oct; 22(5): 436-40.

Baquet CR & Comiskey P. (2000). "Socioeconomic factors and breast carcinoma in multicultural women." Cancer Mar 1; 88(5 Suppl): 1256-64.

Barroso J, MacMillans S., Casey L, Gibson W, Kaminski G, Meyer, J. (2000). "Comparison between African American and white women in their beliefs about breast cancer and their health locus of control." Cancer Nursing Aug; 23(4): 268-76.

Bernstein J, Mutscher P, Berstein E (2000). "Keeping mammography referral appointments; motivation, health beliefs and access barriers experienced by older minority women." Journal of Midwifery Womens Health Jul - Aug; 45(4): 308-13.

Bibb, S. (2000). "Access and late-stage diagnosis of breast cancer in the military health system." Military Medicine Aug; 165(8): 585-90.

Bibb, S. (2001). "The relationship between access and stage at diagnosis of breast cancer in African American and Caucasian women." Oncology Nursing Forum May; 28(4): 711-9.

Breen N, Wesley MN., Merrill RM, Johnson K. (1999). "The relationship of socio-economic status and access to minimum expected therapy among female breast cancer patients in the

National Cancer Institute Black-White Cancer Survival Study." Ethnic Disability Winter; 9 (1): 111-25.

Chu, K.C., Tarone, R.E., Brawley, O.W. (2000). "Breast cancer trend of black women compared with white women." Archives of Family Medicine May; 9 (5): 412-13.

Clark, E. J. (2001). Unequal burden; care disparities. NASW News. Oct: 46; No. 9: 2.

Crump SR, Mayberry RM., Taylor BD, Varefield KP, Thomas PE. (2000). "Factors related to noncompliance with screening mammogram appointments among low-income African American women." Journal of the National Medical Association May; 92(5): 237-46.

Derosé KP, Hawes-Dawson J., Fox SA, Maldonado N, Tatum A, Kington R. (2000). "Dealing with diversity: recruiting churches and women for a randomized trial of mammography promotion." Health Education Behavior Oct; 27(5): 632-48.

Fox SA, Stein JL, Sockloskie RJ, Ory, MG. (2001). "Targeted mailed materials and the Medicare beneficiary: increasing mammogram screening among the elderly." American Journal of Public Health Jan; 91(1): 55-61.

Fredrick Schneiders Research. (1999). Perceptions of how race and ethnic background affect medical care. Menlo Park, CA, The Henry J. Kaiser Family Foundation: Oct; 1-5.

Gates MF, Lackey NR, Brown G. (2001). "Caring demands and delay in seeking care in African American women newly diagnosed with breast cancer: an ethnographic, photographic study." Oncology Nursing Forum Apr; 28(3): 529-37.

Haynes MA & Smedley BD, (Ed). (1999). The unequal burden of cancer. An assessment of NIH research and programs for ethnic minorities and the medically underserved. Washington, DC, National Academy Press.

Joslyn SA& West M. (2000). "Racial Differences in Breast Carcinoma Survival." Cancer 88(1): 114-23.

Mayo RM, Ureda JR, Parker VG. (2001). "Importance of fatalism in understanding mammography screening in rural elderly women." Journal of Women and Aging 13(1): 57-72.

McDonald PA, Thorne DD, Pearson JC, Adams-Campbell LL. (1999). "Perceptions and knowledge of breast cancer among African American women residing in public housing." Ethnic Disability Winter; 9 (1): 81-93.

Menck HR & Mills PK. (2001). "The influence of urbanization, age, ethnicity, and income on the early diagnosis of breast carcinoma: opportunity for screening." Cancer Sep 1; 92(5): 1299-304.

National Cancer Institute. (2001). Strategic plan to reduce health disparities. Bethesda, MD, National Cancer Institute: 8.

National Vital Statistics System. (1998). Breast cancer mortality, CDC, NCHS.

O'Malley MS, Earp JA, Hawley ST, Schell MJ, Mathews HF, Mitchell J. (2001). "The association of race/ethnicity, socioeconomic status, and physician recommendation for mammography: who gets the message about breast cancer screening?" American Journal of Public Health Jan; 91(1): 49-54.

Paskett ED, Tatum CM, D'Agostino R Jr, Rushing J, Velez R, Michielutte R, Dignan M. (1999). "Community-based interventions to improve breast and cervical cancer screening; results of the Forsyth County Cancer Screening (FoCaS) Project." Cancer Epidemiology, Biomarkers and Prevention May; 8 (5): 453-9.

Phillips JM, Cohen MZ, Moses G. (1999). "Breast cancer screening and African American women: fear, fatalism, and silence." Oncology Nursing Forum Apr; 26(3): 561-71.

Phillips JM, Cohen MZ, Tarzian, AJ. (2001). "African American Women's experiences with breast cancer screening." Journal of Nursing Scholarship 33(2): 135-40.

Polednak, A. (2000). "Trends in late-stage breast, cervical and colorectal cancers in blacks and whites." Ethnic Disability Winter; 10 (1): 60-8.

Ries, L.A.G., Eisner, M.P., Kossary, C.L., Hankey, B.F., Miller B.A., Edwards, B.K. (ed.). (2000). SEER cancer statistics review 1993-1997. Bethesda, MD, National Cancer Institute.

Rimer BK, Conway MR, Lyna PR, Rakowski W, Woods-Powell CT, Tessaro I, Yarnall KS, Barber LT. (1996). "Cancer screening practices among women in a community health center population." American Journal of Preventive Medicine Sep-Oct; 12(5): 351-7.

Roetzheim RG, Pal N, Tennant C, Voti L, Ayanian JZ, Schwabe A, Krischer JP. (1999). "Effects of Health Insurance and Race on Early Detection of Cancer." Journal of the National Cancer Institute 91(16): 1409-15.

Ross, H. (2000). Lifting the Unequal Burden of Cancer on Minorities and the Underserved. Closing the Gap, Office of Minority Health, US Department of Health and Human Services.

Sadler GR, Thomas AG, Gebrekristos B, Dhanjal SK, Mugo J. (2000). "Black Cosmetologists Promoting Health Program: Pilot Study Outcomes." Journal of Cancer Education 15(1): 33-7.

SEER. (2001). SEER cancer statistic review 1973-1998 Breast Cancer, National Cancer Institute: 30-32.

Simon, M.S., Gimotty, P.A., Moncrease, A., Dews P., Burack R.C. (2001) "The effect of patient reminders on the use of screening mammography in an urban health department primary care setting." Breast Cancer Research and Treatment Jan,; 65(1):63-70.

Surgeon General. (1996). Physical activity and health: a report of the Surgeon General. Atlanta, GA, US Department of Health and Human Services, Center for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion.

Tessaro I, Eng E, Smith J. (1994). "Breast cancer screening in older African American women: qualitative research findings." American Journal of Health Promotion Mar-Apr; 8(4): 286-92.

Yood MU, Johnson CC, Blount A, Abrams J, Wolman E, McCathy BD, Raju U, Nathanson DS, Worsham M, Wolman SR. (1999). "Race and Differences in Breast Cancer Survival in a Managed Care Population." Journal of the National Cancer Institute 91(17): 1487-91.

Zhu K, Hunter S, Bernard LJ, Payne-Wilks K, Roland CL, Levine RS. (2000). "Mammography screening in single older African American women: a study of related factors." Ethnic Disability Autumn; 10 (3): 395-405.

Annual Report Appendix B

DAMD 17-01-1-0546

Barriers to Early Detection of Breast Cancer Among African-American Females Over Age 55

Virginia J. Smith, Ph. D.
Lincoln University
Lincoln University, PA 19352

Annual Report (9/03-9/04) Appendix B

Data Collection Protocols and Other Methodological Items

An Exploration of Factors Preventing Early Detection of Breast Cancer Among African American Females Over Age of 55

BC996137

Principal Investigator: Virginia J. Smith, Ph. D.
Associate Professor and Director, Multidisciplinary Center
on Aging, Lincoln University

DATA COLLECTION PROTOCOL

The study is designed to identify factors preventing early detection of breast cancer among African-American Females over the age of 55. A modified snowballing approach to sampling will be used to identify 25 female African-American breast cancer survivors over the age of 55 for participation in an interviewing process. The study is being conducted under the auspices of the Multidisciplinary Center on Aging at Lincoln University. The target population for this Center is African-Americans over the age of 55. The age and race criteria for this study were selected for consistency with the Center's target population. For purposes of the study, breast cancer survivor is defined as women who are at least one-year post diagnosis. Women currently in treatment and those who are in remission will not be excluded from the study. Only English speaking subjects will be recruited and all subjects will have the ability to consent for themselves. Initial subjects will be identified by distributing notices to churches, physicians' offices, health centers, and senior centers. Interested persons will be asked contact the Principal Investigator. The investigator will provide a summary of the research using the information in the attached Consent to Participate in Research Form as a guide. Potential subjects not willing to be audio-taped will not be invited to join the study. This conversation will also include opportunities for the potential subject to ask questions. Current subjects will be asked to pass written information (in the form of a flyer) about the study on to others who may want to participate. Any potential subjects identified through this modified snowballing approach will initiate the contact with the Principal Investigator.

The sample size of 25 was selected for two reasons. First, because the project seeks in-depth information, the small sample size of 25 was selected sacrificing breadth for depth, given the time allocated for data collection. Second, given the estimated amount of raw data, it was determined that 25 cases would be manageable by one investigator, given the time limitations.

The Principal Investigator will review the informed consent procedures with each potential subject during a face-to-face interview. Subjects will have three days to consider participation in the study. Those who express continued interest will be asked to sign the consent form prior to the first data collection episode. Only after the consent form is signed by the subject, will the data collection process begin. A copy of the consent form is attached. There will be no direct benefit for subjects in this study.

The interviewing process will be unstructured using open-ended questions. A copy of the interview guide is attached.

Interviews will be conducted for no longer than 120 minutes at a time. If necessary, second follow-up interviews will be conducted. The subject will have a choice of being interviewed in a private office at the facilities of Lincoln University's Urban Center, 3020 Market Street, Philadelphia, PA, or in their homes. If neither of these locations is acceptable to a subject, the researcher will make arrangements to conduct the interview in a neutral location such as a senior citizens center, church, or community center. All interviews will be tape-recorded. Potential subjects not consenting to this tape-recording will not be invited to join the study. Additionally, the interviewer will take notes covering major topics. These notes will be recorded on the interviewer's lap top computer on a separate floppy disk that will be marked with the subject's identification number

Payment of \$50 will be made to the subjects completing the entire interview process as compensation to cover any personal costs. This payment will be pro-rated, as outlined in the consent form, for partial completion of the interview process. This payment will be made in cash and the subject will be asked to sign a receipt that will be used for accounting purposes only. The receipt will only state that the subject participated in an interview for a research project conducted by Lincoln University, the date, the amount, and the Principal Investigator's name. Payment schedule in the event that the interview is terminated by the subject or by the interviewer is detailed in the consent document.

All tapes will be transcribed and erased and destroyed after transcription. Transcripts and interviewer's notes (hard copies and computer disks) will be maintained in a locked filing cabinet for five years, after which time, paper materials will be destroyed and computer disks will be erased and destroyed. Only three study staff will have access to the raw data collected in this study. These are Dr. Smith, Principal Investigator, Frank P. Worts, Assistant Professor, Lincoln University, and Sarah Lowman, clerical staff. All study subjects will be assigned confidential identification numbers by the Principal Investigator, who will maintain a file with all identifying information. This file will be maintained on her personal computer and on floppy disk. The file will be password protected. Only Dr. Smith, Mr. Worts, and Ms. Lowman will have access to the password. This file will be maintained in a locked filing cabinet. The tapes and interview notes will be identified only by the confidential number. All three staff will sign a confidentiality oath.

The content analysis approach will be used for data analysis. NUDIST, software for qualitative data analysis will be used for systematic coding. All transcripts, as well as interviewer notes will be coded in NUDIST. Dr. Smith and Mr. Worts will jointly develop the NUDIST coding system. Each of them will separately code each transcript and meet weekly once coding begins to reconcile any differences in the coding decisions made between the two of them. Once data is aggregated, trends and patterns are identified, and tentative hypotheses proposed, a small group of colleagues within the Lincoln University Community and one external expert (Dr. Linda M. Burton, Director, Center for Human Development and Family Research in Diverse Contexts and Professor of Human Development and Family Studies and Sociology, Penn State University), who are well versed in qualitative research methods, will be convened to review the aggregated findings and make recommendations about the validity of the interpretations.

Additionally, Dr. Burton has agreed to serve as mentor to the Principal Investigator throughout the data collect and analysis processes. Dr. Burton is currently Principal Investigator on two major qualitative studies: 1) Welfare, Children, and Families: A Three-City Study and 2) An Ethnography of Rural Communities, Families, and Children. Dr. Burton and her project staff have already provided training in NUDIST to Dr. Smith and Mr. Worts.

All interviews will be conducted by the Principal Investigator for this study who is:

Virginia J. Smith, Ph. D., ACSW
Associate Professor and Director, Multidisciplinary Center on Aging
Lincoln University
3020 Market Street
voice: 215-590-8205
fax: 215-387-3834
e-mail address: vsmith@lu.lincoln.edu

Dr. Smith holds a masters degree in social work. She is a licensed social worker in the State of Pennsylvania and a member of the Academy of Certified Social Workers of the National Association of Social Workers. She has over 15 years of experiences in client assessment and service planning, as well as individual and group counseling. This background qualifies her to respond to emotional distress. In the event that a subject needs mental health assistance, Dr. Smith will refer her to Elizabeth Hartzell, Ph. D., Psychotherapist, Dr. Hartzell is a member of the Women's Therapeutic Collective, a professional practice group of therapists. Verification of Dr. Hartzell's agreement to accept referrals is attached in the form of her signed letter.

In addition to the Principal Investigator, the two staff persons will have access to raw data. The first is Frank P. Worts, whose role on the project is to assist with literature review and content analysis of raw data, utilizing software (NUDIST) for analysis of qualitative data.

Frank P. Worts, M. S. W., Adjunct Instructor
Lincoln University
3020 Market Street
Philadelphia, PA 19104
215-590-8205

The second person is Sarah Lowman, who will serve as project secretary, responsible for processing compensation to subjects, general record keeping for purchases, transcriptions of tapes and general correspondence.

Sarah Lowman, Secretary
Lincoln University
Lincoln University
3020 Market Street
Philadelphia, PA 19104
215-590-8204

Possible risk of participation in the study is minimal and only related to any difficulty with the content of the questions. Subjects will be informed of their right, without penalty, to discontinue the interviewing process or to refuse to answer a specific question at any time during data collection. Any adverse effects reported to the Principal Investigator in the form of complaints about the interview questions will be reported to the USAMRMC as prescribed in its regulations regarding the protection of human subjects.

The local IRB for this project is:

Lincoln University Institutional Review Board,
Dr. Alvin E. Amos, Chair, Lincoln University
Lincoln University, PA 19352
voice: 610-932-8300, ext. 3555
fax: 610-932-1213

The expected duration for this study is October 1, 2001 through January 31, 2004. The project literature review has been completed. Data collection is expected to occur during the period of July 1, 2003 through September 30, 2003, approximately eight interviews per month. Content analysis using NUDIST will be completed by November 30, 2003. The final report and manuscripts for publication will be completed by January 31, 2004.

If this study protocol is modified, terminated, or extended during the course of the project, the local IRB and HSRRB will be notified for a decision regarding whether or not the protocol or consent document should be amended.

CONSENT TO PARTICIPATE IN RESEARCH

An Exploration of Factors Preventing Early Detection of Breast Cancer Among African American Females Over Age of 55 BC996137

Principal Investigator: Virginia J. Smith, Ph. D., Lincoln University
3020 Market Street
Philadelphia, PA 19104
215-590-8205

You are invited to participate in a research study conducted at Lincoln University by Dr. Virginia J. Smith. You should read the information below and ask questions about anything you do not understand before deciding whether or not to participate.

Purpose of the Study

The purpose of the study is to help discover why for some African American women over the age of 55, breast cancer is identified at later stages.

Procedures

English-speaking African-American women over 55 years of age who were diagnosed with breast cancer one or more years ago are being asked to participate. As a participant, you will be the subject of one or two interviews to be conducted by the Principal Investigator, Dr. Virginia Smith. Total interviewing time per meeting will not exceed two hours. Overall interviewing time if two sessions are necessary will not exceed four hours. During the interview process, you will be asked information about the history of your breast cancer, including how it was identified and treated. You will also be asked about reservations that you may have had about breast cancer detection strategies. You will be asked about your general health beliefs and practices, as well as cultural and family traditions regarding management of health issues. You will also be asked to discuss any spiritual or religious aspects of your health care beliefs and practices.

Potential Risks and Discomforts

Participation in this study will have no direct benefit for those interviewed. The only possible risk of your participation in the study is a minor degree of difficulty with the content of the questions. However, you may refuse to respond to any specific question and you may request that the interviewing be terminated at any time during the process, with no penalty to you.

Initials of Subject

Initials of Interviewer

Alternatives to Participation

Your participation in this study is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue your participation at any time without penalty of loss of benefits. For questions about your rights as a research subject, or if you believe that you have sustained a research-related injury please contact Dr. Alvin Amos, Chair, Lincoln University Institutional Review Board, 610-932-8300, ext. 3555. Significant new findings developed during the course of the research project that may relate to your willingness to continue participating in the study will be immediately made available to you.

Payment for Participation

Compensation for participation will be \$50 to cover any cost to you for participation in the interviewing process. This payment will be made in cash and at the end of the interview. You will be asked to sign a receipt for this payment. If you decide to terminate the interview before it is complete, you will receive partial payment as follows:

- | | |
|---|----------------------|
| • Up to the first 15 minutes | no payment |
| • After the first 15 minutes and up to 45 minutes | \$20 |
| • After the first 45 minutes and up to 75 minutes | \$30 |
| • After the first 75 minutes and up to 90 minutes | \$40 |
| • After the first 90 minutes | full payment of \$50 |

The interviewer may decide to terminate the interview if she determines that this termination is in the best interest of the research. In the event that the interviewer terminates the interview, the above payment schedule will apply.

Confidentiality

All information provided during this interview process will be kept confidential. Although the interviews will be tape-recorded and the interviewer will take notes using a lap top computer on floppy disk, only the three members of the research team will have access to these materials. All three of these persons are aware of the confidential guidelines for this project and have signed confidentiality oaths. All tape-recorded materials will be erased, and tapes destroyed after they are transcribed. The transcriptions will be maintained with interviewer notes in a locked filing cabinet for a period of five years and will be destroyed by paper shredder at the end of this time period. Also at the end of the five-year period, all computer files of original interviews will be erased. If you choose to participate, you will be assigned a confidential study identification number that only the three members of the research team will know. Any reports and other publications that will be prepared will conceal your identity, as well as specific information that may lead to your identity.

Initials of Subject

Initials of Interviewer

An Exploration of Factors Preventing Early Detection of Breast Cancer Among African American Females Over Age of 55 BC996137
Consent Form, Page 3

The U. S. Army Medical Research and Materiel Command officials may review the records of this study as a part of their responsibility to protect human subjects in research.

Results of this study will be made available to those interviewed in the form of a summary report of themes, and patterns that emerged, as well as a list of recommended issues for future study.

Signature of Research Subject

I have received a copy of this consent form and I have been informed that Dr. Smith can be reached at the address and telephone number at the top of this form should I have any questions about the study, either before or after my interview(s). Also, I understand at any time I may reverse my decision to participate in the study and I may refuse to answer any question(s) during the interviewing process.

Printed or typed name of Subject

Signature of Subject

Date

Permanent Address of Subject

City, State, Zip code

Subject's Telephone Number

Virginia J. Smith, Ph.D.
Printed or typed name of Interviewer

Signature of Interviewer

Date

A team of faculty from Lincoln University is conducting confidential interviews with African American breast cancer survivors over the age of 55.

These interviews are a part of a study to develop ideas about how early detection rates for breast cancer can be improved among African American females over the age of 55.

If you are a breast cancer survivor who is African American and over the age of 55 and would like to learn more about this study, please contact the following person:

**Dr. Virginia Smith
Lincoln University
3020 Market Street
Philadelphia, PA 19104
215-590-8205
email - vsmith@lu.lincoln.edu**

Participation in the study is voluntary. There is no obligation to participate in the study. You may call for information and then decide not to participate.

Persons interviewed will be compensated with a payment of \$50.00 to cover any cost of participation.

Annual Report Appendix C

DAMD 17-01-1-0546

Barriers to Early Detection of Breast Cancer Among African-American Females Over Age 55

Virginia J. Smith, Ph. D.
Lincoln University
Lincoln University, PA 19352

Annual Report (9/03-9/04) Appendix C

Power Point Presentation

Findings from 25 Interviews with African American Breast Cancer Survivors over the Age of 55

*A study conducted by:
Virginia J. Smith, Ph. D.*

And

*Frank P. Worts, M.S.W.
Lincoln University
Pennsylvania*

Background

- Health quality and outcomes are worse for African-Americans and other minorities.
 - African-Americans have the highest morbidity and mortality rates in almost every category of diseases, compared to whites.
-

Background

- African-Americans, no matter their income, no matter their illness, will invariably receive health care inferior to that received by whites.
 - Disparities in level of medical treatment for African-Americans receiving Medicare have been documented.
-

Background

- African-Americans under 45 years of age are 10 times more likely to die from complications of hypertension than whites in the same age group.
 - African-American men in Harlem, in New York city, have less of a chance of living to 65 years of age than men in Bangladesh, one of the poorest countries in the world.
-

Background

- African American women who are diagnosed with breast cancer are less likely than white women to survive five years after diagnosis.
 - At all ages, African American women die from breast cancer more often than whites.
 - Breast cancer in African-American women tends to be diagnosed at later stages.
-

Background

- There are still unexplained factors of late diagnosis of breast cancer among African-American females.
 - Few studies address the cultural context issues and those that have provided insight have used qualitative methods.
-

Research Question

- **What are some of the factors preventing early detection of breast cancer among African-American females?**
-

Methodology

- Modified snowball sampling was used to identify 25 subjects.
 - Interviews were conducted by one investigator.
 - Interviews were unstructured following a general schedule of questions.
-

Methodology

Interview Schedule covered:

- General health background
 - Breast cancer diagnosis and treatment
 - Family history of breast cancer
 - Breast cancer detection behaviors prior to diagnosis
 - Reservations about breast cancer detection
 - General health beliefs and practices
 - Spiritual/religious aspects of health beliefs and practices
-

Methodology

- Interviews were tape recorded and notes were taken
 - Transcripts and notes were coded by two investigators: the one conducting the interviews and a colleague on the study
 - Strict human subjects protection was enforced
-

Profile of the Subjects

- 25 African American females over the age of 55 years
 - Living in the Southeastern Pennsylvania area
 - All retired, living on social security benefits
 - All had Medicare benefits, with 80% having supplemental insurance
-

Profile of Subjects

- Fifteen of the 25 were widowed; five were married; five were divorced.
 - The subjects ranged in age from 58 to 87 years. Their average age was 70.25.
 - All were active at senior centers or in support groups
 - All were breast cancer survivors of at least five years. The longest survival period was 52 years. The shortest survival period was seven years
-

Findings

Detection of Breast Cancer

- 8 of the women indicated that their breast cancer had been discovered through a routine self examination process
 - 6 said they found a lump accidentally, or felt something different that prompted them to seek medical advice
 - 7 women said the breast cancer was detected through routine mammograms
 - 4 said that health care providers detected the breast cancer through examination. One of these providers was a holistic practitioner.
-

Findings

Family Background

- Growing up, all respondents remembered having some type of family physician.
 - Only one reported recollection of use of non-traditional health practitioners by their families of origin. All said families use tonics and/or herbal remedies
 - All 25 respondents indicated that diet was very important in their families of origin and that healthy lifestyle meant eating fresh fruit and vegetables.
-

Findings

Family History of Breast Cancer

- 15 of the respondents has no family history of breast cancer
 - 10 had family histories of breast cancer involving female siblings, mothers, and maternal aunts
 - 24 of the respondents indicated that breast cancer was something that their family members did not discuss prior to their diagnosis or the diagnosis of another family member. Many said that cancer was a word that was not mentioned in their homes as they were growing up. One person indicated that it was widely known in her family when relatives had cancer and breast cancer was discussed as a family issue.
-

Findings

Breast Cancer Detection Behaviors Before and After Diagnoses

- 23 of the 25 respondents indicated that they had routine mammograms prior to their diagnoses.
 - All 25 said that since the diagnoses, they had at least annual mammograms.
 - 10 of the 25 said that prior to their diagnoses, they practiced routine breast self examination.
 - At the time of the interviews, 23 respondents indicated that they currently practiced routine breast self examination. The remaining two said they were not opposed to this practice, but just did not think to self-examine on any routine basis.
 - 12 of the 25 women said they had annual visits with gynecologist who examined their breast at least annually. Those with recent diagnosis and treatment (less than 10 years) indicated that they have at least annual follow-up visits with physicians who treated their cancer and these visits include breast examination.
-

Findings

Spirituality

- All of the subjects expressed belief in a higher power and strong spirituality.
 - 23 of the 25 respondents identified a religious affiliation (all Christian)
 - The other two indicated that they believed in the power of prayer
 - 21 of the 25 said without probing that they believe in God's healing power
 - 10 of the 25 said without probing that they believed that their fate was in the hands of God.
-

Preliminary Conclusions

Based on the in-depth interviews with these 25 breast cancer survivors, the investigator has drawn some preliminary conclusions to be confirmed by follow up study with a larger sample, using a quota sampling strategy to increase the heterogeneity of the group of respondents.

Preliminary Conclusions

- For these women, breast cancer was not something that they expected to encounter, even for those who had family histories.
 - Behaviors, including discussion of cancer within the family, changed after their diagnosis.
 - For many of them, their relationships with God were important to the detection of breast cancer and the successful recovery that followed.
-

Limitations of the Study

- The sample size was small and new ideas continued to emerge over the course of the 25 interviews.
 - The modified snowball sampling strategy resulted in a homogeneous sample of persons who were very active in either senior centers, support groups, or religious activities.
-

Recommendation for Future Research

- The study should be repeated, expanding the sample size to 50.
 - The expanded group of subjects should be recruited using quota sampling to increase the heterogeneity of the sample.
-

Annual Report Appendix D

DAMD 17-01-1-0546

Barriers to Early Detection of Breast Cancer Among African-American Females Over Age 55

Virginia J. Smith, Ph. D.
Lincoln University
Lincoln University, PA 19352

Annual Report (9/03-9/04) Appendix D

Draft Manuscript

Preliminary Results About Spirituality From Qualitative Interviews With A Small Sample Of African-American Breast Cancer Survivors

Authors: Virginia J. Smith, Ph. D.
Frank P. Worts, M.S.W.
Lincoln University, PA

Introduction

Notwithstanding the national stabilization rates of mortality from breast cancer, cancer mortality among African American women is approximately 28% higher than white women (American Cancer Society, 2000). Moreover, African American women who are diagnosed with breast cancer are less likely than white women to survive five years after diagnosis, the rate among African American women is 71%, compared to 86% among white women (Ries, et al., 2000; Johnson 2002).

In the age groups of 30-54 years and 55-69 years, African American women have the highest mortality rates. In the 70 years and older age group, the mortality rate for white women exceeds that for African American women (SEER, 2001).

Multiple studies have established the fact that the differential breast cancer mortality rate between African American and white women is due to the fact that a larger percentage of African American breast cancers are diagnosed at later, less treatable stages (SEER, 2001; Baquet & Comiskey, 2000; Joslyn & West, 2000; Chu, et al., 2000; Aziz, et al., 1999; Phillips, et al., 2001; Polednak, 2000.)

It is crucial to identify and understand the factors that are associated with late diagnosis breast cancer for African American women. The factors are complex and interrelated. Several studies indicate that the health care system, economic access and its practices as well as demographic factors are associated and interrelated with late-stage breast cancer diagnosis: Several studies have indicated that beliefs about healthcare, including the health delivery system, and spiritual beliefs may explain some of the disparities around breast cancer outcomes for African-American women (Green, 2004.)

An exploratory study was conducted in which 25 African-American female breast cancer survivors were interviewed. The purpose of this exploratory study was to identify barriers to early detection of breast cancer among African-American females over the age of 55. It was designed to result in the articulation of hypotheses for further study. The literature review confirmed that there are disparities in rates of early diagnosis of breast cancer among African-American women between the ages of 55 and 70. Also, it showed that there are still unexplained factors of late diagnosis of breast cancer among African-American females. Additionally, only a few studies address the cultural context issues and those that have provided insight have used qualitative methods. Based on the findings from the literature review, a semi-structured interview protocol was developed to explore beliefs and practices around breast cancer and breast cancer screening among a small sample of up to 25 African-American breast cancer survivors over the age of 55. There were several commonalities among the women interviewed.

For most of them, breast cancer was detected and treated during its early stage. There was a sense among them that breast cancer was not something that the women expected to encounter, even for those with family histories of the disease. Further, most of the women reported that until they were diagnosed with breast cancer, their adult daughters and female siblings were not very conscientious about breast self examination and regular mammograms. Most of the women reported that cancer was not something that they talked about in their immediate and extended families prior to their diagnoses.

Emerging from these 25 interviews were several interesting issues for future research, one of which was relating to spirituality. Most of the women were very spiritual. Twenty reported some degree of involvement in religious activities. But all 25 expressed that they were spiritual and practiced some type of prayer, meditation, and/or spiritual reading. The belief that there is a higher power that controls destiny was specifically stated or implied in all of the 25 interviews. A specific analysis was conducted to identify the individual perspectives of the 10 women who specifically, without probing indicated a belief that their fate was in the hands of God. This article presents the findings of this analysis of perspectives.

Methodology

A modified snowball sampling strategy was used to recruit 25 subjects. The subjects were offered the options of interviewing in their homes, at nearby senior centers, or at the offices of the investigators. All subjects selected either the senior center setting or invited the investigator to their homes. All interviews lasted at least one hour and none exceeded two hours. The average interview time was 99 minutes. The 25 interviews were conducted by one investigator. This feature, by design, resulted in the same person hearing every story. The interviews were also tape recorded. Although the tapes were transcribed and coded by two different investigators prior to electronic content analysis, for purposes of this manuscript, the principal investigator, who has conducted all of the interviews, listened to every tape and reviewed her notes for explicit or implicit statements relating to spirituality and/or the role of destiny in the outcome of illness. The interview process was open ended, using an unstructured schedule covering the following topics:

- General health background
- Breast cancer diagnosis and treatment
- Family history of breast cancer
- Breast cancer detection behaviors prior to diagnosis
- Reservations about breast cancer detection
- General health beliefs and practices
- Spiritual/religious aspects of health beliefs and practices

Profile of the Subjects

The subjects ranged in age from 58 to 87 years. Their average age was 70.25. Fifteen of the 25 were widowed; five were married; five were divorced. Two of the respondents were employed. One was receiving social security disability payments. One was a retired federal employee, receiving a federal pension. The others were retired, all having worked prior to retirement age

and were receiving social security benefits. About one half of those receiving social security benefits also received some other pension payments. All were breast cancer survivors of at least five years. The longest survival period was 52 years. The shortest survival period was seven years.

Summary of Key Findings

Key findings from the overall study included:

Detection of Breast Cancer

- 8 of the women indicated that their breast cancer had been discovered through a routine self examination process
- 6 said they found a lump accidentally, or felt something different that prompted them to seek medical advice
- 7 women said the breast cancer was detected through routine mammograms
- 4 women had second incidences of breast cancer affection the opposite breast. In all four cases, the cancer was detected through annual mammography.
- 4 said that health care providers detected the breast cancer through examination. One of these providers was a non-traditional practitioner.

Family Background and History of Breast Cancer

- 15 of the respondents has no family history of breast cancer
- 10 had family histories of breast cancer involving female siblings, mothers, and maternal aunts
- 24 of the respondents indicated that breast cancer was something that their family members did not discuss prior to their diagnosis or the diagnosis of another family member. Many said that cancer was a word that was not mentioned in their homes as they were growing up. One person indicated that it was widely known in her family when relatives had cancer and breast cancer was discussed as a family issue.
- Growing up, all respondents remembered having some type of family physician.
- Only one reported recollection of use of non-traditional health practitioners by their families of origin. All said their families used tonics and/or herbal remedies.
- All 25 respondents indicated that diet was very important in their families of origin and that healthy lifestyle meant eating fresh fruit and vegetables.

Breast Cancer Detection Behaviors Before and After Diagnoses

- 23 of the 25 respondents indicated that they had routine mammograms prior to their diagnoses.
- All 25 said that since the diagnoses, they had at least annual mammograms.
- 10 of the 25 said that prior to their diagnoses, they practiced routine breast self examination.

- At the time of the interviews, 23 respondents indicated that they currently practiced routine breast self examination. The remaining two said they were not opposed to this practice, but just did not think to self-examine on any routine basis.
- 12 of the 25 women said they had annual visits with gynecologist who examined their breast at least annually. Those with recent diagnosis and treatment (less than 10 years) indicated that they have at least annual follow-up visits with physicians who treated their cancer and these visits include breast examination.

Spirituality

- All of the subjects expressed belief in a higher power and strong spirituality.
- 23 of the 25 respondents identified a religious affiliation (all Christian)
- The other two indicated that they believed in the power of prayer
- 21 of the 25 said without probing that they believe in God's healing power
- 10 of the 25 said without probing that they believed that their fate was in the hands of God.

Summary of Perspectives On Spirituality

For purposes of this article, the analysis was seeking to identify specific perspective about the belief that there is a higher power that controls destiny. Among the 25 respondents, 10 indicated this belief. The remainder of this article will discuss the perspectives of these 10 respondents regarding this belief that God controls destiny.

One theme that emerged regarding this was the notion that God had given them breast cancer so that they could become involved in awareness activities for others to encourage routine detection behaviors and to support survivors by providing educational programs. Several women indicated that the support groups are very helpful because they provide information about what can be expected after treatment, or "What the doctors did not tell us." Eight of the ten said that they were involved in at least one support group. Two respondents were leaders in support groups.

A second theme that emerged was the idea that God can heal any disease or illness and that the important ingredient is faith. This idea includes the belief that sometimes adversity such as disease is presented as a test of our faith. According to one of the respondents, "Faith is the essential ingredient." Five of the women believed that ministers of the faith have specific healing qualities given by God and these are more effective as the faith of the healer is increased.

Although both of these themes were present in the interviews, there was also the by-line that God expects us to take care of our bodies. The reference was made by seven of the 10 women that "Our bodies are temples."

Future Research

This study will be repeated, expanding the sample and probing issues of spirituality to a greater depth. Additionally, the original participants will be re-visited to delve more deeply into the issues of spirituality, specifically the two themes discussed above.