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13. ABSTRACT (Maximum 200 Words)

Breast cancer screening programs offer the greatest promise for early detection but rates of participation in free screening programs have been disappointing for challenged populations. The purpose of the current study is to elaborate the beliefs and culturally embedded meanings that a population of low income, uninsured African American women hold toward breast cancer and breast cancer screening. During Year 03, Phase 1 activities were completed, including contact attempts to all potentially eligible women in the population data base. All Phase 1 interviews have been transcribed and technically verified. All interviews except 10 have been inductively coded. Formal presentations of study results-to-date have been presented to three professional groups, including the Susan G. Komen Breast Cancer Foundation, Puget Sound Affiliate. Results from the coded interview data offer compelling reasons why NEW educational, outreach and training materials are needed in order to more successfully engage fiscally challenged African American women in breast cancer screening programs.

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Introduction

The purpose of this Idea Grant is to describe and elaborate the perceptions, beliefs, and culturally embedded meanings about breast cancer and breast cancer screening reported by a population of low income, uninsured African American women. There were two phases to the study: Phase I involved case intensive interviews; these were completed during this past funding year. Phase 2 will involve focus groups and will be the main focus of this next funding year. Both phases involve a population-based sample of low income, uninsured African American women in Washington state who were eligible for but declined to receive a free screening mammogram when outreached by an indigenous community worker. Accomplishments in the past funding year, Year 03, are described next. We have been granted a no-cost extension for doing Phase 2 work for Year 04 activity.

Body of Annual Report

Statement of Work

The approved Statement of Work and each related activity is contained in Figure 1.

Figure 1: Approved Statement of Work

1. Train intermediaries on protocol for inviting women into study.**
2. Formalize linkages between recruitment sources and study team.**
3. Establish linkages between outreach workers and interviewers and study team.**
4. Develop spreadsheets for tracking target and accessed sample.**
5. Identify target sample of women for interviews.**
6. Convene Community Advisory Committee to pre-screen interview schedule.**
7. Conduct intermediary contact calls to eligible women.**
8. Conduct interviews for Phase 1 by trained interviewers.**
9. Train Project Manager on open coding..**
10. Conduct meetings of interview team..**
11. Transcribe interviews for Phase 1..**
12. Do open coding of interviews.**
13. Convene meeting of Community Advisory Council.**
14. Convene on-going meetings of Community Advisory Council.**
15. Complete Phase 1 interviews.**

** Denotes that all activities have been completed. Details follow below.

STATEMENT OF WORK

1. **Train intermediaries on protocol for inviting women into study.**

STATUS: Completed.

Dr. Lewis trained clinic outreach workers, including clinic-based site intermediaries, on the protocol for inviting eligible women into the study in Year 03. This included training clinic intermediaries for a "third wave" of recruitment that was conducted for this past funding year (Year 03). Lewis trained four clinic based intermediaries that were linked to the medical clinics that were available to offer free screening mammograms to the women.

STATEMENT OF WORK

2. **Formalize linkages between recruitment sources (agencies subcontracted to outreach eligible women) and the investigative team.**
3. **Establish linkages between outreach workers and interviewers and investigation team.**
6. **Convene Community Advisory Council to pre-screen interview schedule for study.**

STATUS: Completed.

During the past funding year we continued to carry out our Community Advisory Council meetings. We presented our results-to-date to this council at two different meetings and have begun to work with them to generate a new grant based on study results from the Phase 1 interviews. A summary of the content of the handout at the meeting during November, 2002, follows. This handout relates to a portion of the categories that were identified from the coded interviews. Specifically, we were reporting what women said to the question, "What are the greatest fears, if any, you have about breast cancer?" The categories of responses are underlined in the text below; the numbered text are the verbatim statements from the study participants. The words of the categories are stated in the words of the women; they are not the words of the research team.

Breast cancer will take your life.

1. I just know that it [br ca] will take your life if you have it… because I do worry about death.
2. I do think that they don't have a cure for cancer, no type of cancer.
3. So when you get cancer, you're through.
4. He [Lord} may just prolong your life to give you a little longer to live, you know, but it eventually comes back and get [sic] you and kills you.
5. Breast cancer might take my life.
6. Breast cancer could kill me.
7. If you don't find it in time, it'll spread and end my life.

Finding breast cancer from a mammogram would be devastating.

1. My biggest fear, than when I do go and have one [mammogram], I might get some harsh news.
2. Since I've never been checked for it [br ca], that I would find out I have it.
3. I don't really fear it [br ca], but I think if I was told that I had it, I would be fearful.
4. And I go this one particular [for a mammogram] and I have it [br ca], I'm gonna be particularly devastated.
5. Fear of the unknown; I dread next week [mammogram appt].

You won't get breast cancer if nobody (sic) in your family never had it.

1. I really don't have any fears about breast cancer. Nobody in my family ever had it…I'll never get it.
2. I was led to believe that it wasn't important for me to have regular screening because it doesn't run in my family.

Having one breast would bother me if I had a man.

1. That would be hard trying to initially find a mate and to feel relaxed okay and feel feminine.
2. I'd probably be forever celibate.
3. I'd always feel guilty and shy [even if I did have augmentation].
4. [I'd feel] exploited, being rejected, being laughed at, taunted [by men].
5. …wondering if he [mate] thinks he's hurting me or wondering if he's pulling away, being repulsed
6. I would not want a man to even see me, period.

Having part of your body gone makes you feel less than a woman.

1. A mastectomy has got to be the most challenging [sic] that anybody could have.
2. [with a mastectomy] I just can't imagine, you know, what a woman goes through.
3. They feel less of a woman because part of their body is gone.
4. I could see where someone who had lost their breast wouldn't feel normal anymore, you know, like a woman.

When you open your body up [breast surgery], the cancer spreads to some other part of your body.

1. Once you open that area up [the breast], wherever the cancer's located, it just send it throughout your body.
2. When they open you up and cut on you, I think it's freeing the cancer.
3. They cut on you and the next thing you know it's spread to some other part of your body.
4. If you had never let them cut you, you would never ever got air, and then it wouldn't be bad.

Study results-to-date were presented to the Tacoma Pierce County Health Department and their community partners as well as to the Board of Directors of the Susan G. Komen Foundation, Puget Sound Affiliate. This latter Foundation is the single largest contributor to free screening mammograms for fiscally challenged women in our region, second only to the Breast & Cervical Health Program of Washington State. The Komen Foundation has encouraged us to submit a new grant based on our study results that we have presented at their most recent Board meeting. We have already begun to generate that grant and plan to submit it for the September 15, 2003 deadline.

Membership of the Community Advisory Committee (CAC) includes members and supervisors from the recruitment sources as well as additional stakeholders from the community, local, regional, and state-wide government and agencies. The composition of this Committee continues to be essential to the on-going support and access to the study population as well as to the future dissemination of study findings into sustainable outreach activities and programs for fiscally challenged African American women in Washington state. Ms. Phillips-Angeles provided the leadership for these meetings and worked with Lewis and members of the advisory committee to set the agenda.

Members of the Community Advisory Committee include Dr. Maxine Hays, M.D., the senior Health Officer of the state in the Washington State Health Department; Cherie Minear, Program Director, Puget Sound Affiliate, Susan G. Komen Breast Cancer Foundation; Dr. Cobie Whiten, PhD, state epidemiologist for the Washington Breast & Cervical Health Program; Tara

Chestnut, Program Coordinator, YWCA-Encore Plus, Tacoma; Etta Williams, Senior Services of Seattle/King County; Shelly Cooper-Ashford, Center for Multicultural Health; Karen Fennell, C.H.N, Pierce County Breast & Cervical Health Program; Dr. Patricia Dawson, M.D., among others.

STATEMENT OF WORK

4. **Develop spreadsheets for tracking target and accessed sample.**
5. **Identify target sample of women for interviews.**
8. **Conduct intermediary contact calls to eligible referred women.**

STATUS: Completed.

In Year 03, we conducted a third wave of contacting the eligible study participants, expanding to 10 or more phone contacts by the intermediary before we identified the woman as "not reachable." This outreach involved Dr. Lewis training 6 new community-based site intermediaries as well, a new Assistant Research Manager, and a new interviewer.

We plan to write a research paper on the methodology of outreaching highly vulnerable, often mobile, sometime homeless, fiscally challenged African American women. The endurance, both methodologically and emotionally, that was required by our study team to "stay with it" to outreach and attempt to contact these study participants exceeded everything that has been written in the methods research literature. Lewis has been conducting field research since 1983 with extramural grants and nothing in these prior experiences prepared her for the onerous recruitment efforts that were needed for the current grant. For example, some of the listed phone numbers for the women were homeless shelters; some were phone numbers at which the woman no longer lived; some were phone numbers for multiple other persons who were unable to say when the woman might be home to receive the phone call. Our spreadsheets used to track the timing, day of week, and frequency of phone calls was fastidiously maintained in order to maximize our effectiveness. [No women's names were used, only code numbers unless the woman gave the intermediary permission to release her identification to the interviewer.]

We have now completed all outreach contact calls for all Phase 1 women that are in our recruitment county's population database. Dr. Ling Song, our CoPI and county epidemiologist, updated that population database throughout the past funding year, including comparing phone numbers in the data base with the most current phone numbers available through other records, including medical clinic records locally. [Study team members remained 'blind' to these numbers; only Dr. Lin Song, Ph.D. had access to that confidential data base, consistent with the human subjects protocol that was approved.]

Lewis hired and trained a new Assistant Research Project Manager in this past funding year, Rachel Bennett. Under the direction of Lewis, Bennett assumed day-to-day responsibility for the detailed documentation of all aspects of accrual, attrition, and completion of study interviews. All this information, including information on reasons for refusing to participate, were maintained in detailed, fastidious notes on a spreadsheet. We will be using that spreadsheet to generate the research methods paper on the challenges and realities of outreaching a population-based vulnerable population of potential study participants.

STATEMENT OF WORK

7. Conduct interviews for Phase 1 by trained interviewers.
10. Conduct meetings of interview team.
15. Complete Phase 1 interviews.

STATUS: Completed.

We have now identified, outreached, and attempted 6 or more [often 10 or more] contact attempts to every woman in the population database. All interviews were conducted within the protocol guidelines and have resulted in "thick description" of what fiscally challenged African American believe about cancer, breast cancer, and early detection and screening.

There are virtually no more eligible women in the BCHP database. We are now ready to move to Phase 2, during which we will conduct focus groups of women who consented to be re-contacted by our study team after Phase 1 interviews were completed. Focus groups will constitute the main new component of our Year 04 work.

STATEMENT OF WORK

9. Train Project Manager on open coding.
11. Begin transcription of first set of interviews.
12. Begin open coding of interviews.

STATUS: Accomplished.

We have transcribed and 100% verified the technical accuracy of all the interviews that were completed for Phase 1. The Project Manager was not trained to do the open coding because she did not have sufficient time available to conduct that activity. Instead, Dr. Cobie Whiten, PhD [a member of the Advisory Community Council], and the Co-PI, Ellen Phillips-Angeles, were technically trained to do the inductive coding. To date, we have coded all but 10 interviews using inductive coding methods. In the next funding year, we will further refine the codes as well as refine the explanatory theory about why women chose to not obtain a free screening mammogram when outreached. An example of the detail with which the transcribed interviews are coded follows; the data below are from ONE PAGE of a multiple-page summary of the coding of ONE question for a SUBSET of the interviewed women who participated in Phase 1 interviews. The data below relate to the interview question, What is the worse thing you can imagine if you were to be diagnosed with breast cancer? The digits in parentheses are the code numbers of the individual interviewed women.

I would die (#109, 188)
Dying (#10943, 397)
Dying (#11, 189)
next thing you know they're gone (#11, 206)
Dying and leaving my family (#111112, 326)
I was going to die (#11114, 300)

Dying (#14, 415)
Dying (#16553, 207)
it will take my life and take me from my family (#17976, 146)
How long am I going to be here (#18389, 668)
you're cutting into my time and I ain't read to go yet (#18389, 672)
it cuts your life short, and that's it (#18389, 679)
Dying…that I would probably not live as long as I'd like to live (#21478, 111)
To leave this space, this plant, without having really done what I wanted to do (#21478, 408)
not surviving (#48, 432)
so to say that I don't fear death would….is not a lie, but to say that I'm ready to go, I have to say I'm not ready to go (#7, 329)
It's just the death, um, I'd probably withdraw more into myself (#93, 601)
Death, it's the final, it's a death sentence (#93, 646)

<u>Telling me I have cancer</u> (#111115, 377)
Just be knowing it (#125rw, 282)
Just to know that I had breast cancer…just the thought of it (#125rw, 286, 290)
I just don't want to ever be really sick or diagnosed with cancer (#125rw, 304)
I don't know…the worst would be if he [doctor] tell me I have cancer (#12603, 322)
That would be the worst thing, if I was diagnosed with it (#14988, 267)
is the mammogram something that will or won't cause me to have some kind of operation or something, surgery or whatever (#15868, 547)
the worst thing is that it's cancerous, you know (#15868, 557)
If it's malignant, I'll be thinking about dying, if it's benign, I would be thinking about surviving (#16553, 220)
You say this is what's wrong with my body, does it, do I look any different (#93, 610)

<u>It was too late to fix</u> (#109, 187)
you're never really sure how fast it's gonna progress (#11, 201)
That it [cancer] would be so far-gone, they would tell me I only have a short time to live (#111113,222-223)
That's about the worst thing for me. The fact that, it would be so far-gone that I couldn't do anything but pray to God (#111113,271)
them not detecting it in time (#17976, 144)
that it was in the probably the last stages of it where there was no prevention or anything to stop the breast cancer (#44, 143)
if I was a stage 4 and no matter what they did….that it was iffy (#7, 322)
your mortality hit you right in your face again (#7, 323)
to find out if it was curable and to give it the fight of my life (#7, 333)

Similar detailed coding has been carried out on all of the interview questions that were used for Phase 1 interviews. In addition to coding the Phase 1 interviews using open coding inductive methods, in Year 03 we have also reviewed the most recent published literature on attitudes and beliefs about breast cancer and screening in the published literature. A summary of the beliefs in that research literature by others is summarized below. In Year 04, we will compare our study results with these prior published results. Our preliminary analyses revealed that most of the beliefs and attitudes in our Phase 1 interviews are NEW results and not contained in the prior published studies.

Belief Statements in Recent Published Literature in Studies of African-American Women

Beliefs about mammograms

Women believe that mammograms can cause breast cancer.[2]

Women who are not regular mammogram users believe that mammograms can cause breast cancer.[2]

Women who are not regular mammogram users believe that mammograms are painful.[2, 5]

Women who miss their mammogram appointments believe that getting a mammogram is an embarrassing experience.[4]

Women believe that cost prevents them from getting a mammogram.[5, 8]

Women who live in rural areas worry about the cost of mammograms.[8]

Women who live in rural areas believe the cost of a mammogram prevents them from getting one.[8]

Women who miss their mammogram appointments believe that there is no reason to get a mammogram if a woman is not sick.[4]

Women who miss their mammogram appointments or don't get mammograms believe that a woman does not need a mammogram if she has no symptoms or no problems with her breasts[4, 5]

Women believe that a mammogram is not necessary if there are no problems with their breasts.[5?]

Women who do not obtain regular mammograms believe that mammograms cannot detect cancer early.[2]

Women who live in rural areas do not get mammograms because they don't understand how they are performed.[8]

Beliefs about God/Powerful Others

Women believe that God controls their health.[1, 7]

The more a woman believes in God as the one who controls her health, the less likely she is to adhere to CBE and mammography.[1]

Women who doubt the value of early diagnosis of breast cancer believe in powerful others.[7]

Women who believe that all women can be cured from breast cancer have strong beliefs in powerful others.[7]

Women with the greatest belief in powerful others believe that early diagnosis gives one longer to worry and be sick.[7]

The more education a woman has, the less she believes that her health is controlled by chance or powerful others.[7]

Beliefs about breast cancer (including causes)

Women do not believe that breast cancer incidence increases with age.[2]

Women do not want to know if they have breast cancer.[8]

Women do not get mammograms because they do not want to know if they have breast cancer.[8]

Beliefs about breast cancer (cures/early diagnosis)

Women who miss their mammogram appointments believe that breast cancer cannot be detected early[4]

Women who do not get mammograms are not confident that breast cancer can be cured.[3]

Women are unsure if about half of the people with breast cancer can be cured.[7]

Women are unsure if they benefit from the early diagnosis of breast cancer.[7]

Women doubt the value of early diagnosis.[7]

Women believe that all women can be cured from breast cancer.[7]

Women's worries

Women worry about their health[7, 5, 8]

Women worry about finding breast cancer.[5, 8]

Women who worry about finding breast cancer do not get mammograms.[5, 8]

Breast cancer prevention beliefs

Women do not know or are unsure if they can prevent breast cancer.[7]

Beliefs about death/dying

Women who believe in chance believe that all women with breast cancer will die.[7]

Women do not believe that having a mammogram decreases their chances of dying.[5]

Miscellaneous beliefs
Women believe that health is a matter of luck.[7]

Reportable Outcomes

1. A population data base of uninsured and fiscally challenged African American women can be successfully phone contacted by "cold calls," but it takes may require 10 phone contact attempts to successfully reach the women.
2. Most women, when successfully reached by an intermediary, are willing to be contacted to be interviewed.
3. The greatest number of women "lost" to the study was due to 3 factors: non-functioning phone contact numbers; ineligibility determined by conversation with the women by the study intermediary [e.g., women stated they obtained a screening mammogram from another source, not BCHP]; or no one answered the phone when the intermediary contacted a working phone number. [We hypothesize that "caller ID" may have kept the callee from answering the intermediary's contact attempts.]
4. Completed elicitation interviews yield detailed description and elaboration of participants' beliefs, perceptions, and attitudes toward breast cancer and breast cancer screening. Results from these interviews include data that have not been previously identified in the research literature.
5. A Community Advisory Committee of stakeholders and community members is able to assume a major advisory and participatory role as supportive community partners in the conduct and direction of a population based interview study.

6. Selected reportable results from a <u>subset</u> of the Phase 1 interviews follows; the referent to women in the text below are the study participants

Women fear the unknown. The unknown relates to both the unknown of whether the mammogram will detect breast cancer and also whether the disease will be advanced when it is detected. Study participants do not view early screening and detection of breast cancer as a medically neutral series of events. Instead, they believe that early screening and detection only introduces problems or troubles when a woman is free of breast symptoms.

Women fear mortality from breast cancer. Although some know and talk about the importance of early detection, some also believe that there is really no cure for the disease, no matter when it is detected. In short, the diagnosis of breast cancer, even early stage breast cancer, becomes a kiss of death, not hope for recovery and a full life unrelated to breast cancer. In fact, there is only one interview that is coded so far in which a "successful" outcome from breast cancer was either known or identified.

Treatment for breast cancer, including surgery and chemotherapy, conjures up dread and negativity in the women. They fear they will no longer be a whole woman with a mastectomy; they fear rejection, exploitation, and taunting from men. Only one of the interviewees in the coded data to date said anything positive about treatment for the breast cancer. With breast cancer, the women would lose their sense of self as a whole woman and will be rejected by men.

Overall, this means that there is no win-win with early detection through screening mammograms for these women. If the disease is caught early, they do not believe in a cure. If the disease results in a mastectomy, they have two responses: the disease will spread because of the surgery itself or they will feel disfigured and less of a woman. If they get treatment from chemotherapy, they think the chemo will do things, bad things, to their body. Even hair loss would be unbearable for some.

Personal risk for breast cancer is totally misunderstood. Women believe that if there is no history of breast cancer in their family, they personally have no risk for the disease. Our speculation is that their perceived low personal risk for breast cancer would further push them away from choosing a screening mammogram. For some women, breast cancer is a non-issue. This is much more than believing they are not susceptible to the disease. It means that breast cancer is not even on their personal radar screen as being relevant to them.

Breast surgery and the spread of breast cancer is totally misunderstood. Some women think that exposure to air either introduces the cancer or the actual surgery itself spreads the cancer to other parts of the body. This again creates a no-win situation: Biopsy is viewed as spreading the cancer, not detecting the disease and thereby allowing for successful treatment.

The women's models of causation and risk factors for breast cancer are not the same models that are known in the medical literature. Risk factors for study participants included, among other factors: large breasts, smoking, and [alcoholic] drinking.

Data obtained to date suggest that new informational, educational, and outreach materials are needed, including those that directly address the "incorrect" risk factors; the beliefs that screening procedures damage the woman or cause her "problems" when she is symptom free; and which deal directly with quality of life that can be positive post-surgery, including for sexually active women. Death and suffering stories need to be complemented with quality of life survivorship stories.

The data also have major significance for the development of NEW cultural training materials and workshops for medical providers and their health care assistants, including radiology technicians, nurses, and physicians, among others.

Conclusions

Completed interviews from Phase 1 have yielded thick descriptions of culturally embedded factors and beliefs that affected the study participants' decisions to decline participation when outreached for a free breast cancer screening program. Many of these factors have not been documented in prior published research.

In the next year, we will conduct focus groups in order to further refine results obtained from the completed Phase 1 interviews. Year 04 [no cost extension] will put primary emphasis on Phase 2 focus groups as well as on professional papers and presentations. We will also plan to submit a new grant to develop new educational outreach materials and related training materials.

References

Abbott, R., Barber, K.R., Taylor, D.K., & Pendel, D. (1999). Utilization of early detection services: a recruitment and screening program for African American women. *Journal Health Care Poor and Underserved, 10*(3):269-280.

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

Ansell, D., Lacey, L., Whitman, S., & Phillips, C. (1994). A nurse-delivered intervention to reduce barriers to breast and cervical cancer screening in Chicago inner city clinics. *Public Health Reports, 109*(1), 104-111.

Antony, A.K. (1999). How African-American women look at breast cancer. Perceptions from rural North Carolina. *NC Medical Journal, 60*(5):284-287.

Bailey, E.J., Erwin, D.O., & Belin, P. Using cultural beliefs and patterns to improve mammography utilization among African-American women: the Witness Project. *Journal National Med Assoc, 92*(3):136-142.

Barroso, J., McMillan, 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, 23*(4): 268-276.

Bernstein, J., Mutschler, P., & Bernstein, E. (2000). Keeping mammography referral appointments: motivation, health beliefs, and access barriers experienced by older minority women. *Journal of Midwifery Women's Health, 45*(4):308-313.

Bottomley, A., & Jones, L. (1997). Breast cancer care: women's experience. *European Journal of Cancer Care, 6*(2), 124-132.

Bowen, D., Hickman, K.M., & Powers, D., (1997). Importance of psychological variables in understanding risk perceptions and breast cancer screening of African American women. *Women's Health, 3*(3-4):227-242.

Brown, L.W., & Williams, R.D. (1994). Culturally sensitive breast cancer screening programs for older black women. *Nurse Pract., 19*(3):21, 25-26, 31.

Burnett, C. B., Steakley, C. S., & Tefft, M. C. (1995). Barriers to breast and cervical cancer screening in underserved women of the District of Columbia. *Oncology Nursing Forum, 22*(10), 1551-1557.

Caplan, L.S., Helzlsouer, K.J., Shapiro, S., Wesley, M.N., & Edwards, B.K. (1996). Reasons for delay in breast cancer diagnosis. *Preventive Medicine, 25*(2):218-224.

Cassard, S.D., Weisman, C.S., Plichta, S.B., & Johnson, T.L. Physician gender and women's preventive services. *Journal Women's Health, 6*(2):199-207.

Champion, V, & Menon, U. (1997). Predicting mammography and breast self-examination in African American women. *Cancer Nursing, 20*(5):315-322.

Cimprich, B. (1998). Age and extent of surgery affect attention in women treated for breast cancer. *Research in Nursing & Health, 21*(3), 229-238.

Clark, N.M. & McLeory, K.R. (1995). Creating capacity through health education: What we know and what we don't know. *Health Education Quarterly, 22*(3), 273-289.

Conn, V. S. (1997). Older women: social cognitive theory correlates of health behavior. *Women Health, 26*(3), 71-85.

Crane, L. A., Leakey, T.A., Rimer, B.K., Wolfe, P., Woodworth, M.A., & Warnecke, R.B. (1998). Effectiveness of a telephone outcall intervention program to promote screening mammography among low-income women. *Preventive Medicine, 27*(5, Pt. 2), S39-49.

Crump, S.R., Mayberry, R.M., Taylor, B.D., Barefield, K.P., & Thomas, P.E. (2000). Factors related to noncompliance with screening mammogram appointments among low-income African American women. *Journal National Medical Association, 92*(5):237-246.

Danigelis, N.L., Roberson, N.L., Worden, J.K., Flynn, B.S., Dorwaldt, A.L., Ashley, J.A., Skelly, J.M., & Mickey, R.M. (1995). Breast screening by African-American women:

insights from a household survey and focus groups. *American Journal of Preventive Medicine, 11*(5):311-317.

Davis, R. E. (1998). Coming to a place of understanding: the meaning of health and illness for African American women. *Journal of Multicultural Nursing and Health, 4*(1), 32-41.

Dolan, N. C., Lee, A. M., & McDermott, M. M. (1997). Age-related differences in breast carcinoma knowledge, beliefs, and perceived risk among women visiting an academic general medicine practice. *Cancer, 80*(3), 413-420.

Eng, E. (1993). The Save our Sisters Project. A social network strategy for reaching rural black women. *Cancer, 72*(3 suppl):1071-1077.

Erwin, D.O., Spatz, T.S., Stotts, R.C., & Hollenberg, J.A. (1999). Increasing mammography practice by African American Women. *Cancer Practice, 7*(2):78- 85.

Flynn, B.C. (1992). Healthy Cities: A model of community change. *Family & Community Health, 15*(1), 13-23.

Flynn, B.C., Rider, M., & Ray, D.W. (1991). Healthy cities: The Indiana Model of Community Development in Public Health. *Health Education Quarterly, 18*(3), 331-347.

Franzoi, S. L., & Koehler, V. (1998). Age and gender differences in body attitudes: a comparison of young and elderly adults. *International Journal of Aging and Human Development, 47*(1), 1-10.

Freudenberg, et al. (1995). Strengthening individual and community capacity to prevent disease and promote health: In search of relevant theories and principles. *Health Education Quarterly, 22*(3), 290-306.

Friedman, L. C., Neff, N. E., Webb, J. A., & Latham, C. K. (1998). Age-related differences in mammography use and in breast cancer knowledge, attitudes, and behaviors. *Journal of Cancer Education, 13*(1), 26-30.

Ghafoor, A., Jemal, A., Cokkinides, V., Cardinez, C. et al. (2002). Cancer statistics for African Americans. *CA, A Cancer Journal for Clinicians, 52*(6), 326-341.

Greenlee RT, Hill-Harmon MB, Murray T, Thun M. Cancer Statistics, 2001. *Cancer.* 2001;51(1):11-36.

Haigney, E., Morgan, R., King, D., & Spencer, B. (1997). Breast examinations in older women: questionnaire survey of attitudes of patients and doctors. *British Medical Journal, 315*(7115), 1058-1059.

Hebert-Croteau, N., Goggin, P., & Kishchuk, N. (1997). Estimation of breast cancer risk by women aged 40 and over: a population-based study. *Canadian Journal of Public Health, 88*(6), 392-396.

Heidrich, S. M. (1998). Older women's lives through time. *Adv Nurs Sci, 20*(3), 65-75.

Hoffman-Goetz, L., Mills, S.L., (1997). Cultural barriers to cancer screening among African American women: a critical review of the qualitative literature. *Women's Health, 3*(3-4):183-201.

Kagawa-Singer, M. (1995). Socioeconomic and cultural influences on cancer care of women. *Seminars in Oncology Nursing, 11*(2), 109-119.

Kalichman, S.C., Williams, E., & Nachimson, D. (2000). Randomized community trial of a breast self-examination skills-building intervention for inner-city African-American women. *Journal American Medical Women's Association, 55*(1):47-50.

Kaluzny, A. D., Rimer, B., & Harris, R. (1994). The National Cancer Institute and guideline development: Lessons from the breast cancer screening controversy. *Journal of the National Cancer Institute, 86*(12), 901-903.

Lawson, E.J. (1998). A narrative analysis: a black woman's perceptions of breast cancer risks and early breast cancer detection. *Cancer Nursing, 21*(6):421-429.

Lowe, J. I., Barg, F. K., & Bernstein, M. W. (1995). Educating African-Americans about cancer prevention and detection: a review of the literature. *Social Work in Health Care, 21*(4), 17-36.

Mahloch, J., Thompson, B., & Taylor, M. (1998). Use of qualitative methods to develop a motivated video. *Journal of Health Education, 29*(2), 84-88.

McDonald, P.A., Thorne, D.D., Pearson, J.C., & Adams-Campbell, L.L. (1999). Perceptions and knowledge of breast cancer among African-American women residing in public housing. *Ethn Dis,* 9(1):81-93.

McLeroy, K.R., et al. (1995). Creating capacity: Establishing a health education research agenda for special populations. *Health Education Quarterly, 22*(3), 390-404.

Miller, A. M., & Champion, V. L. (1997). Attitudes about breast cancer and mammography: racial, income, and educational differences. *Women and Health, 26*(1), 41-63.

Minkler, M. & Wallerstein, N. (1997). Improving health through community organization. In K. Glanz, F. Marcus Lewis & B. Rimer (Eds.), *Health behavior and health education: Theory, research and practice, 2nd edition*, (pp. 257-287). San Francisco: Jossey-Bass.

Nemcek, M.A. (1989). Factors influencing black women's breast self-examination practice. *Cancer Nursing, 12*(6):339-343.

Phillips, K., Glendon, G., & Knight, J. A. (1999). Sounding board. Putting the risk of breast cancer in perspective. *New England Journal of Medicine, 340*(2), 141-144.

Phillips, J.M., Cohen, M.Z., & Moses, G. (1999). Breast cancer screening and African American women: fear, fatalism, and silence. *Oncology Nursing Forum, 26*(3):561-571.

Resnick, B. (1998). Efficacy beliefs in geriatric rehabilitation. *Journal of Gerontological Nursing, 24*(7), 34-44.

Reynolds, K. D., West, S. G., & Aiken, L. S. (1990). Increasing the use of mammography: A pilot program. *Health Education Quarterly, 17*(4), 429-441.

Rimer, B. K. (1994). Interventions to increase breast screening. Lifespan and ethnicity issues. *Cancer*, *74*(1, Suppl.), 323-328.

Rothman, A. J., Salovey, P., Turvey, C., & Fishkin, S. A. (1993). Attributions of responsibility and persuasion: Increasing mammography utilization among women over 40 with an internally oriented message. *Health Psychology*, *12*(1), 39-47.

Ruffing-Rahal, M. A., Barin, L. J., & Combs, C. J. (1998). Gender role orientation as a correlate of perceived health, health behavior, and qualitative well-being in older women. *Journal of Women Aging*, *10*(1), 3-19.

Schwartz, A. J., Lerman, C., Hughes, C., Peshkin, B. N., & Biesecker, B. (1998). Psychological distress in women seeking genetic counseling for breast-ovarian cancer risk: the contributions of personality and appraisal. *Annals of Behavioral Medicine*, *19*(4), 370-377.

Schwartz, M. D., Lerman, C., Audrain, J., Cella, D., Rimer, B., Stefanek, M., Garber, J., Lin, T. H., & Vogel, V. (1998). The impact of a brief problem-solving training intervention for relatives of recently diagnosed breast cancer patients. *Annals of Behavioral Medicine*, *20*(1), 7-12.

Silliman, R. A., Dukes, K. A., Sullivan, L. M., & Kaplan, S. H. (1998). Breast cancer care in older women: sources of information, social support, and emotional health outcomes. *Cancer*, *83*(4), 706-711.

Stoddard, A. M., Rimer, B.K. Lane, D., Fox, S.A., Lipkus, I., Luckmann, R., Avrunin, J.S., Sprachman, S., Costanza, M., Urban, N. (1998). Underusers of mammogram screening: Stage of adoption in five U.S. subpopulations. The NCI Breast Cancer Screening Consortium. *Preventive Medicine*, *27*(3), 478-487.

Tessaro, I., Eng, E., & Smith, J. (1994). Breast cancer screening in older African-American women: qualitative research findings. *American Journal of Health Promotion, 8*(4):286-292.

Underwood, S.M. (1999). Breast cancer screening among African American women: addressing the needs of African American women with known and no known risk factors. *Journal National Black Nurses, 10*(1):46-55.

Wyatt, G. K., & Friedman, L. L. (1998). Physical and psychosocial outcomes of midlife and older women following surgery and adjuvant therapy for breast cancer. *Oncology Nursing Forum, 26*(4), 761-768.

Zapka, J. G., Costanza, M.E., Harris, D.R., Hosmer, D., Stoddard, A., Barth, R., Gaw, V. (1993). Impact of breast cancer screening community intervention. *Preventive Medicine, 22,* 34-53.

Zhu, K., Hunter, S., Bernard, L., Payne-Wilks, K., Roland, C., Everett, C., Feng, Z., & Levine, R. (2000). An intervention study on screening for breast cancer among single African-American women aged 65 and older. *Ann. Epidemiol., 10*(7):462-463.

Zhu, K., Hunter, S., Bernard, L.J., Payne-Wilks, K., Roland, C.L., & Levine, R.S. (2000). Mammography screening in single older African-American women: a study of related factors. *Ethn. Dis., 10*(3):395-405.