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***Recruitment of African American Women for Research on Breast Cancer Early Detection:
Using Culturally Appropriate Interventions***

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Abstract

Rural, Southern, African American, women comprise a population that can be difficult to reach for health education. With the health disparity regarding early detection of breast cancer greater among African American women than Caucasian women, a successful program for recruitment of participants is needed. Recruitment strategies used in a study using a 2-group, pre-post intervention design with a booster treatment and a follow-up at 1 and 2 months post-intervention design is described. Innovative recruitment methods were implemented to include snowballing, community participation, rural churches, and culturally appropriate interventions. Study findings included a successful recruitment of 159 rural African American participants with 86% retention in the intervention group and 68% retention in the control group. Implications for

future studies include using collaborative work between different agencies within rural communities to reach underserved minority populations. Nurses are important partners to reach women in their own communities.

Keywords: recruitment, African American, women, rural, breast cancer, research, nurses, education

Recruitment of African American Women for Research on Breast Cancer Early Detection: Using Culturally Appropriate Interventions

African American women (AAW) have the highest mortality from breast cancer of any minority group in the United States.^{1,2} Despite the fact that breast cancer survival rate could be as high as 97% if the cancer is found early, survival rate for African American women is approximately 78%.¹ Although the inclusion of African American women in clinical trials was a guideline proposed by the National Institutes of Health (NIH) as early as 1993,³⁻⁵ the number of African American women who participate in clinical trials remains minimal.⁵⁻⁸ For example, in a randomized clinical trial, the Women's Health Initiative (WHI), only 8,000 of 164,500 (4%) participants were African Americans,⁹ far less than their 13% proportion in the population.¹⁰ Although the investigators acknowledged differences in recruitment and randomizing women and women of color, no specific reasons for non-participation were reported by the researchers.⁹

Purpose

Healthy People 2010¹¹ included a goal of decreasing disparities in cancer mortality. To reach this goal, adequate data related specifically to the disparate populations are needed. With regard to breast cancer mortality, strategies to increase the number of African American women, who choose to participate in research studies, are needed. These strategies may remove barriers or they may increase attractiveness of participation. Ideally, strategies to reach racially and culturally diverse groups should be handled with a theoretical model of cultural competence. The purpose of this article is to describe the effective use of a model of cultural competence to recruit African American women for a breast health education program with an ultimate impact on breast cancer mortality.

The Breast Health Education Program Study

The basis of this article was a research study to test the effects of a culturally specific breast education intervention for high risk AAW of 1) selected behavioral risk factors, 2) psychosocial responses, 3) attitudes toward breast self-

examination (BSE), 4) compliance with BSE, and 5) proficiency of BSE performance.¹² Selected behavioral risk factors were fat intake, sedentary life style, and inadequate fiber intake. Psychosocial responses were perceived stress, perceived barriers to BSE, perceived barriers to clinical breast examination (CBE), ineffective coping, and low self efficacy. Attitudes toward BSE included perceived benefits of BSE and perceived benefits of CBE. Compliance with BSE included the number of times each month the women performed BSE. Proficiency of BSE performance included scoring of number of lumps found, while performing BSE on silicone breast models. The women lived in rural areas of a predominantly rural southern state.¹²

To recruit and retain the needed number of AAW, the investigator applied a transcultural assessment model of nursing.¹² This approach resulted in recruiting 159 rural AAW from 7 rural counties of 1 southern state. Of the 70 women recruited, N= 60 (86%), were retained in the intervention group, and of the 86 women recruited, N= 60 (68%), were retained in the control group.¹² This rate of attrition is higher than those of other studies, such as Coward,¹³ Reed and associates,¹⁴ and Fouad, et al.⁹ It appeared that a higher rate of recruitment and participation was related to the use of a transcultural assessment model.¹²

Review of Literature

Many barriers to the recruitment of African Americans in research studies are documented in the literature, as well as, strategies to overcome the barriers. Several of the major barriers and strategies are included here.

Barriers to Recruiting African Americans

Mistrust of research and medicine can be common in the African American community, stemming from situations such as the notorious Tuskegee study.^{6 14-20} In the Tuskegee Syphilis Study, African American men with the syphilis virus were recruited and studied for long term effects of syphilis, under false pretense.²¹ When a cure was found for syphilis, the participants in the study did not receive the medicine, and in fact were given false information.²¹

In a study by Mouton and Associates²² 32% of AAW reported a lack of trust in scientists as compared to only 4.1% of Caucasian women. Another research group, Adderly-Kelly and Green,¹⁶ reported needing a two year span to build trust within an African American community prior to completing data collection.

Socioeconomic factors, such as cost of screenings, transportation, and time spent from work, often reduce awareness of or receptivity to research participation.^{13,15,23} In a study by Nichols and associates,²³ cost issues of participants included time away from work to participate in the study, as well as travel costs. Across all six recruitment sites, 6.1% (n= 74) of participants cited issues related to data collection length as a reason for attrition, while only 2.9% reported travel costs as the reason for attrition.²³

Perceptions of helplessness, powerlessness, or fear were other barriers to recruitment of research participants.^{15,18,24} In a related sample, African American men and women reported that fear of cancer was a deterrent from getting proposed cancer screenings.¹⁸ Also, some African Americans may see the results of treatments being unsuccessful, which increases their fear and perceptions of helplessness.^{15,24}

Cultural Beliefs as Barriers

Several researchers reported cultural attitudes toward breast cancer mortality as barriers to recruitment. Lannin and associates¹⁹ surveyed 2000 women, including 46% AAW, about cultural attitudes toward breast cancer mortality, and found that AAW have more cultural beliefs that delayed treatment than White females ($p < 0.001$). African Americans were also found to hold significantly more cultural beliefs that discouraged women from seeking medical care, such as reliance on divine intervention,^{19,25,26} general fatalism, the attitude that death is inevitable and disease may be the will of God,¹⁵ and general perception of secrecy regarding cancer diagnosis.¹⁵ Lack of knowledge about the seriousness of a breast lump and a belief in folk medicine were also more prevalent among African Americans.¹⁹ In one of the questions related to whether doctors experiment with people by “cutting a person’s cancer” (performing surgery), 6% of Caucasians agreed with the statement, compared to 17% of the African Americans.¹⁹

Successful Strategies for Recruitment

Several recruitment and retention strategies have been reported as successful for the African American population. Several researchers suggested developing ties with the African American community.^{9,15,20,27-29} Other researchers suggested collaborating with persons in the community through collaborating with churches.^{15-17,20,26,30} Moreno-John and associates²⁰ suggested going within the community to complete research rather than expecting the participants to go to outside establishments. Abernethy and associates¹⁵ suggested having a familiarity with participants, as an aide to successful recruitment.

Other strategies for overcoming barriers to recruitment included offering free or reduced cost screenings,^{15,28,29} and providing transportation needs.^{9,15,28,29} In one study with the Women's Health Initiative, transportation was needed and provided for 70% of the minority populations, as a strategy to enhance recruitment.⁹

One major cultural issue within the African American community addressed during recruitment was building trust.^{9,15-18,20,28} Abernethy and associates¹⁵ suggested dispelling the mistrust with education. When working with African American men, during prostate cancer screenings, researchers successfully recruited 655 men by dispelling fears and fatalistic views with practical solutions and education related to negative past experiences.¹⁵ The value of informing participants of study progress and outcomes, and of investing presence and service in the community are also strongly supported.^{15,20}

Strategies Using Media

The usefulness of various media for recruitment has been evaluated.^{9,28} Brochures or flyers that were individually designed by the minority serving clinics were more successful than generic brochures.⁹

Other effective mass media include group presentations^{9,30} and snowballing (telling a friend).^{7-9,31} In a research study to engage high risk African Americans in a physical activity program, 49% of participants with low educational levels were obtained through snowballing, compared to 32% of the overall sample.²⁷ Fouad and associates⁹ surveyed minority participants in the Women's Health Initiative study and found that in the African American community, group presentations with "Name-A-Friend" at churches was the most effective recruitment strategy.

Newspapers were found to be ineffective in one study,²³ but effective in others.^{9,28} Fouad and associates⁹ found that the media, newspaper articles, and advertisement were regarded as effective by 88% of African American participants, followed by television and radio news reports at 66%.

The University of North Carolina's Center on Minority Aging for the Durham Elders Project researchers recruited approximately 182 African Americans aged 65 years and older and retained them on a database for 5 subsequent studies.²⁰ These researchers reported several reasons for recruitment success, such as: 1) collaborating with community leaders, community churches, and community organizations; 2) having a research office located within the community; 3) providing information to participants during and after completion of the study; and 4) making visits in the homes of seniors.

Providing service activities to meet the needs of the community, outside of the research study, such as health fairs, guest speaking, and assistance after a hurricane, was also highly effective.²⁰

Transcultural Assessment Model

The Breast Health Education Program and the recruitment and retention strategies were guided by a theoretical framework of culturally appropriate interventions, the Giger and Davidhizar Model of Transcultural Assessment.³² The Giger and Davidhizar Model of Transcultural Assessment (GDMTA) was developed as a means for nurses to understand cultural expression of diverse groups of people and then to use the information obtained to provide culturally competent care.³²⁻³⁵ Components of the model are communication, space, social organization, time, environmental control, and biological variations. GDMTA components were thought to influence recruitment of AAW in the Breast Health Education Program and were thought to enhance retention of study participants.

Communication

Description. Communication is the continuous process by which one person can affect another person through behaviors, whether verbal or nonverbal.^{32,36} To provide culturally competent care, which includes conversations used in recruitment of African American women into a study, the nurse must be aware of ways to effectively communicate the importance of breast health.

Strategies. Some specific interventions appropriate for providing care to AAW given by Giger and Davidhizar include attentive listening, unhurried demeanor, focused assessment of beliefs and fears, availability of AA female to provide information, social talk to initiate intervention, use of a caring tone in voice, and giving simple explanations for interventions. In application of the Transcultural Assessment Model to the recruitment and retention of the study, interventions specific to this model were used as strategies. As part of the recruitment strategy, communication was started with the local facilitators in the African American communities. The investigator, foreseeing a need for establishing trust, targeted churches as the site for recruitment. Working with established networks was a means to communicate the purpose of the research study to the women in a non-threatening mode and a means of working within established social organizations. In some cases the investigator was able to depend on long-established trust, since she had assisted with local health fairs, presented health information, and answered questions about medical care of family members in

previous encounters with participants. Flyers, which included pictures of AA women, information in familiar terminology, and pleasing to the eye, were posted in drug stores, beauty shops, restaurants, churches' bulletins, and bulletin boards.

Prior to each educational session, AA females provided conversations regarding community events, social networks, and family members in an unhurried and caring demeanor. The actual educational intervention was completed in an unhurried format, using terminology the women understood. The investigator also invited potential participants to nominate or recruit others, a sampling method known as snowballing.¹⁵ Communication with friends and family was common in the AA community. In 50% of the groups, there were two or more participants from the same family as a result of the snowballing effects.

Space

Description. Space is defined in relationship to personal space. Personal space can be described in relationship to the area around their personal bodies that people would like to maintain for themselves without the invasion of another person. The behavior of individuals in their personal space (spatial behavior) encompasses sensory stimulation from the external environment and their awareness of the stimulation from the internal environment.³² Although AAW have close personal spaces as a rule,³⁶ nurses should assess this for each client. When people's personal space is respected, they feel safer and less anxious in their own territory and are more likely to disclose personal ideas or feelings.³⁶

Strategies. In planning the implementation of the Breast Health Education Program, the concept of space was considered. The location of the meeting was determined by the individual church leader or community leader. The majority of the meetings within churches occurred in the church dining area. In preparing the seating arrangements, the chairs were placed around tables. Participants were allowed to select and position their chairs, thus providing them with control over their personal space. The participants sat in close proximity to the other participants in all of the intervention groups and control groups. The comfort of the research sessions was a deciding factor in the women telling other women about the session.

Social Organization

Description. Social organization, which is defined by Giger and Davidhizar,³² is the manner by which a group organizes itself around particular units. A person learns cultural behavior, acquires knowledge and internal values through the

process of enculturation or socialization. Enculturation occurs as a result of participation in a variety of social groups, for which all parts of group participation are important in the total makeup of the individual's being. Important social groups for many AAW include familial groups, religious groups, and ethnic minority groups. For the AA culture family plays an important role in the enculturation process with the family being the basic unit of society.³⁶ It has been hypothesized that many AAW still depend on large kinship networks, which include neighbors, family members, and friends that give assistance with both psychological and sociological support.³² The church or religious group can also be a part of the network for AAW to promote self-esteem and maintain culture.³⁶

Strategies. In recruiting participants for the study, the social organizations of churches, beauty shops, community centers, and women's sewing groups were approached. Much of the successful recruiting efforts occurred through one woman telling others in her network of friends or relatives. When asked about contact persons in the community, ministers of churches were some of the first names mentioned by participants and contact was then made by the researcher.

The local facilitator also contacted a long-established breast cancer survivor group six months prior to the targeted implementation day. The breast cancer survivors group was well known in the community due to the group's participating in several health-related events in the churches prior to the present study. The survivor group's members introduced the researcher to pastors and women leaders within the local churches, as a means of setting up the breast health programs. Churches, being one of the common social networks in the AA community, were an optimal source for obtaining participants. Once the pastors of the local churches gave approval, information regarding the educational programs was placed in flyers, church bulletins, and pamphlets. In churches where she was less well known, the investigator enlisted the assistance of a female leader within the church to recruit participants at meetings after church. The women networked around a lunch served by the researcher. Of the clusters of groups for data collection, 65% took place within church groups.

Time

Description. Time is defined as social time, "systems of time that have diverse meanings and therefore diverse consequences on social interactions."^{32p118} Within the construct of time, the temporal pattern, temporal orientation, and temporal perspectives are discussed. For example, as among most other ethnic groups, some AAW may be future oriented and set goals accordingly to have structured schedules. Others are present oriented and examine needs in terms of the relevancy of the here and now. For clients who are past oriented, historical events may be used to justify present

reactions to situations.³²

Strategies. In recruitment and retention for the study, plans were made in the design of the intervention to include sessions that could be completed in 1-2 hours or 3-4 hours depending on the participant. Although the investigator started sessions on time, there were always late arrivals. This was assumed to indicate whether participants were present or future oriented, with those on time considered future oriented and those who came late as present-oriented. These orientations were accommodated in several ways as the investigator anticipated that the comfort of the sessions would be a major factor in word-of-mouth for attending future sessions or offerings of the entire intervention. The investigator spent the extra time to make each participant feel comfortable, so the persons who were late were given time to catch up without penalizing the ones that were on time. Being conscious of whether the participant was future or present oriented in relationship to time made the investigator spend time accordingly. The future oriented participants- those who came on time- usually were the first to complete the questionnaires and the demonstration sessions. Participants could leave after completion of the components of the study; however, sometimes they chose to remain to socialize. Using an unhurried atmosphere for the present oriented participants, the investigator spent longer time in one-on-one teaching sessions.

Environmental Control

Description. The concept of environmental control encompasses the individual's perception of ability to direct factors in environment or to plan activities that control nature.³² When the individual and the environment are in a mutually balanced reciprocal relationship, a state of optimal functioning or an efficacious health status is achieved.³² If people do not believe they can control the environment, optimal health is considered out of the individual's contextual control, and they are said to have an external locus of control for health. Conversely, those who see themselves as capable of controlling nature or health outcomes are said to have an internal locus of control.^{32,33}

Strategies. During the educational sessions, the research instruments were designed to measure some of these perceptions of environmental control. In observing the participants during the educational sessions, different loci of control were readily apparent from comments of participants. Statements like "Only God knows what we will die from;" "You can do all that you can do, then God takes over;" showed external locus of control. To foster an internal locus of control that would facilitate healthful change the PI introduced the concept that God wants each woman to take care of her body. The stories given by the cancer survivors, which emphasized the desire of the survivors to protect their bodies from the harm of cancer, also promoted an internal locus of control.

Biological Variations

Description. Biological variations are the differences that occur in the biological makeup of the individual in response to racial, cultural, ecological, and environmental factors.^{32,33} It is postulated that some AAW have health care practices generally associated with learned-patterned behaviors giving rise to the development of high risk factors for breast cancer. These health care practices may include preferences for high fat, high sodium foods that may increase susceptibility to breast cancer.³²

Strategies. Some of these concepts of biological variations guided the design of the recruitment of the Breast Health Education Program to improve the retention of participants. The dominant concept of the intervention and the majority of time were spent on biological variations. The high risk factor of race was emphasized during the educational session to encourage monitoring of biological variations. Explanations of how little exercise, lack of adequate intake of fruits and vegetables, and lack of early detection of breast cancer impacted the mortality of African American women related to breast cancer was discussed in detail by the African American nurse. Also, the breast cancer survivors emphasized the use of mammography and CBE to detect breast cancer early.

Discussion/ Conclusions

The application of a culturally appropriate assessment model for recruitment of African American women into a breast health education program and implementation of the program was successful overall, but both useful and non-useful efforts were identified and are reported here. The lessons learned by a novice researcher can be helpful for future research endeavors.

Successful recruitment strategies obtained from the use of Transcultural Assessment Model³² included the social organization of the church to include pastors and church leaders; kinship networks within known communities to provide for snowballing; and building trust within the communities. The success of recruitment was markedly different based on trust building. Several churches, where the investigator was known and trusted, included many participants, who also participated in the study. However; many of the church groups, where the investigator was not known included many participants, who did not participate in the study. Some of the recruitment assistants within several churches or groups guaranteed at least 20 participants at an educational session, to have only three women from a congregation of 150 women attend the recruiting meeting. Many of the recruiting meetings were conveniently placed right after church services

with lunch served. Frequent phone calls, visits to the churches, revisiting support groups in the community, and publication of the study in the church bulletins were added but progress was very slow. After eight months of effort only 40 of the needed 120 were obtained from this community. In the community where the investigator was well known, 80 women were recruited and educated in only four months. Recruitment in unfamiliar territory took longer time periods for data collection to allow for trust building, as compared to a short time in a familiar territory. Other researchers found building trust as an effective recruitment strategy,^{15,20} as well as networking or telling a friend.³¹

Other successful strategies were the inclusion of an African American nurse and African American breast cancer survivors. Being an African American nurse was helpful because many AAWs would prefer to be taught by another African American.³⁶ The breast cancer survivors were effective because they too were African American, and they were seen as true insiders in regard to the problems of breast cancer.

Flyers, posters, and church bulletins were not effective methods of recruitment. This is consistent with other studies.²⁹ The researchers in the Kolawole et al study²⁹ had very little response to flyers, or church bulletins with only 1-4% of the 615 participants stating that these was their recruitment methods. The more successful methods in the present study included word of mouth, similar to previous studies.^{9,27,31}

During the implementation, the use of the Giger and Davidhizar's model was effective. Such strategies as seating arrangements, beginning sessions on time, and discussing how God wants women to maintain a healthy body were all obtained from the model. The cultural significance of having teachers from the same ethnic group was also suggested by the model.

Implications for Practice and Research

It must always be considered that issues other than racial background may influence participation in research, so utmost care must be taken not to fall into perceptions of stereotyping. Working with any specific population must include attention to a range of demographic issues, such as culture, environment, socio-economic situation, and a variety of other factors. When working with populations of African American women, researchers and nurses in practice could consider some of the culturally appropriate interventions for recruitment of participants into educational programs. After experiencing the positive and negative aspects of recruiting 120 African American women into a breast health educational program, insight was gained into effective recruitment strategies. Some recommendations for future recruitment of African American

women include the following: 1) Collaborate with leaders in the community, including church leaders; 2) Allow additional time for trust building within new communities; 3) Utilize persons from the same ethnic background to recruit and implement program; and 4) Accentuate the positive aspects of the individual's locus of control in order to encourage a change in behaviors. For both clinical education and research, education with African American women is likely to be better accepted if the educator or researcher is known and trusted in the community. Although using persons from the same ethnic background may not guarantee success, efforts should be made to accommodate the participants. Churches are indeed an appropriate place for offering health education. Practitioners and educators should be prepared for a need for trust building. The use of testimonials is helpful in that neither the researcher nor the educator may have experienced cancer. These culturally appropriate interventions applied to recruitment can increase the number of African American in research studies in an effort to decrease the overall breast cancer mortality of this group.

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