Family Breast Cancer Education: A Model for African American Women

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Abstract

The purpose of this study, funded by the American Cancer Society, was to increase knowledge and understanding, i.e., the willingness and ability to discuss, of breast cancer in southern minority women and their families. A family model of health education guided the research questions. (a) To what extent will an action research intervention increase knowledge about the causes and treatment of breast cancer in minority women? (b) To what extent will an action research intervention increase willingness to talk with family members? The t-test analysis of a 67-item, self-administered survey indicated significant increases in knowledge of cancer and in their willingness to talk with family members about breast cancer. In addition, they reported increases in comfort level about discussing breast cancer as well as willingness to talk with others about their own (possible) positive diagnosis. We infer that increased comfort level and willingness to talk with others has a relationship to increased awareness of breast cancer.

Key Words: African American, breast cancer, southern women
Introduction

The National Cancer Institute (2006) (1), a component of the National Institutes of Health, estimates that, based on current rates, 12.7% of women born today will be diagnosed with breast cancer at some time in their lives. The American Cancer Society (Breast Cancer Facts & Figures 2007-2008) (2) presented a range of information. Breast cancer accounts for about one out of every three cancers in women in the US, making it the most common cancer diagnosis in women. In the United States, 95% of new breast cancer cases occur in women 40 years old and older. African American women have a slightly higher incidence rate of breast cancer (i.e., the number of new cases per 100,000 persons) than European American women before age 40; however, European women have a higher incidence rate after age 40.

Disparities in cancer mortality abounds. In the US, between the years 2000-2004, 97% of the breast cancer deaths were in women 40 years old and older. According to the most recent data, mortality rates continue to decline in European American women. For example, in the decade of 2001-2004, the rate decreased by 3.7% annually, however, African – American women are more likely to die from breast cancer than European American women. (American Cancer Society, Surveillance Research, 2003 (3). While the decrease in breast cancer mortality is attributed to early detection and improvements in treatment, these differences in mortality rates are also attributed to differences in access to medical care and to socioeconomic and cultural factors (Susan G. Komen Breast Cancer Foundation & NC Triad Affiliate) (4).

Nationally, there are also differences in the relative 5-year survival rates of breast cancer among European American and African American women. For European American women, the survival rate is 90% and for African American women the survival rate is 77%. Although African American women have a slightly lower incidence rate of breast cancer - 119.4 as compared to the incidence rate of 141.1 for European American women before age 40 – the mortality differential is 34.7 for African American women as compared to 25.9 for European women.

Several factors contribute to these breast cancer disparities. The factors associated with late stage at diagnosis include: lack of health insurance, lower incomes, additional illnesses, lower socioeconomic status, unequal access for medical care, and disparities in treatment. Other contributing factors can be grouped in three categories: exposure to carcinogens, occupation, diet and nutrition; knowledge, attitudes, and practice; health and medical resources and biological factors. (Baquet & Gibbs, 1992) (5).

Clearly, there are numerous challenges to addressing the inequities of breast cancer survival among African American women. A family model of health education was used to address these concerns.
Context of the Study

In the state of North Carolina, although African American women are less likely to get breast cancer than European American women, i.e., an incidence rate of 182 compared to 161.8 per 100,000, they are most likely to die of breast cancer, i.e., a mortality rate of 36.2 compared to 24.9 per 100,000. North Carolina Cancer Registry, 1997-2001(6). In North Carolina deaths due to cancer were 22.7%. These data are an important context for this study because breast cancer disparities in the state of North Carolina mirror the national breast cancer disparities.

The geographic area of this study was Forsyth County, North Carolina. This county had a total population of 306,067 people. Of this number 52% were female. African-Americans made up approximately 26% of the population; Hispanics were 3.7%; and European Americans were 69% of the population. The overall median age was 36 years old. The educational attainment of the population of adults 25 years of age and older was reported as 45% had a high school education or less; 20% had some college; and 35% had associate, college and other advanced degrees. The marital status in the population of those 15 years and older was reported as 27% never married; 55% married; 3% separated; 6% female widowed; 6% female divorced. Income (in 1999) for the residents was reported as 10% less than 10K; 19% 10-24,999K; 30% 25-49,999K; 20% 50-74,999K; 10% 75-99,999K; 11% 100+K. (U.S. Census, 2000). (7) In addition, Forsyth County had a higher rate of breast cancer per 100,000 (181.7) than the State of North Carolina (145.9). (North Carolina State Center for Health Statistics, 1996-2000). (8)

A comparison of European American (white) and African American female breast cancer reveals that Forsyth County follows national and state norms, i.e., a higher incidence of female breast cancer in European American women. Fifty percent of African American women are diagnosed in the early stages of breast cancer as compared to 60% of European American women diagnosed in the early stages. (North Carolina Cancer Registry, 1997-2001). (9) This research project - similar to others in the target area (Paskett, et al, 1999) (10) - sought to address these disparate breast cancer data. However, different from other studies, this project included minority women and their families.

Description of a Family Model of Health Education

One of the fundamental principles of human development is that development of individuals occurs in the context of their social and political environments. This context has both proximal and distal characteristics. Proximal interpersonal relationships are family, friends, peers, and significant others; their more intermediate relationships are (extended) family-school-neighborhood-community; and their more distal relations are governing
structures, economic and cultural institutions, pervasive ideologies and philosophies. Therefore the application of these principles would have the female family member with breast cancer residing and interacting with (in) a family system.

The family model of breast health education posits the view that individuals, families and communities have assets. This framework of assets evolved from two types of applied research: prevention and resiliency. These two constructs are therefore the basis of the family assets. Within the context of the family system, prevention addresses the proactive factors of knowledge and understanding of breast cancer while resiliency address those factors that increase the family’s ability to both addresses adversity and to overcome it. (Benson, 2003) (11.) It also addresses the family’s ability to be flexible, make adjustments, and to formulate new norms and new “normal” behaviors and relations. This extensive and intensive knowledge of family relations, as well as an expansive repertoire of behaviors is the criteria that family, i.e., community members are viewed as family experts. Family developmental assets provide an approach that serves as the basis for the complementary use of community-based participatory research. The Family Model of Health Education (FMHE) utilizes the following theoretical foundation:

- Ecological systems theory
- Family developmental assets
- Community-based participatory research (C-BPR)
- PRECEDE - PROCEED
- Cultural competency

Ecological Systems Theory

Systems theory, as conceptualized by Bertalanffy (Nichols & Schwartz, 2001; (Piercy, Sprenkler, & Wetchler, 1996) (12, 13) and later by Bateson (Olsen, 1993) (14) has several main tenets. First, systems are seen as open to and interacting with, their environments. Another tenet is that the system evolves – is constantly changing and has vibrancy – because it is fluid as opposed to rigid. A third tenet is that each system is a “sub-system” of a larger system. Fourth, the whole system is greater than each part, i.e., each sub-system. These tenets apply not only to the biological sciences, where they originated, but also to the social sciences. The two most applicable aspects of systems theory to this study are the explanation of homeostasis within the family system and circular causality. When applied to families, homeostasis refers to the efforts of family to maintain or regain normality when faced with cancer diagnosis or treatment. Circular causality refers to connectedness – whereas change in any sector of the system affects the entire whole system. Thus,
a family system is more than a collection of people; its individual members influence one another in many ways.

The ecological theory of Urie Bronfenbrenner (1988, 1989, 1995) (15, 16, 17) is a type of systems theory - one that emphasizes the social context of relationships as well as circular causality. It is a contextual environmental systemic view that consists of five systems “surrounding the individual: the micro, the meso, the exo, the macro, and the chrono. The microsystem is those relationships most proximal to the individual. Examples of elements of the microsystem are family, school, faith-based organizations, neighbors, and health services. Meso systemic relationships are relationships between elements of the microsystem. For example, when a female, through her relationships in her faith group, learns about the advantages of monthly self-breast exams via information distributed in her place of worship by the local health services center. Elements of the exosystem are characterized by more distal relationships. For example, a change in spouses’ medical coverage of the allowable forms of treatment that Medicaid/Medicare covers affects her individual treatment plan. The macrosystem is characterized by the philosophy, attitudes and ideologies of a particular culture. An example of this is how the female breast cancer patient processes her treatment options. She may not choose to have a mastectomy because she believes she will have a distorted body, that her partner or spouse will no longer think of her as attractive, that she will be an incomplete woman, or that she did something to deserve the disease. She may also feel devalued by political and economic policies that make her treatment (or access to treatment) less than fair and equitable to other prevalent diseases. The chronosystem addresses the patterns and transitions of the relationships over time: a young African American woman who hears consistently from the world around her that her color and her hair make her less beautiful than other women may not value herself the way that she should and may accept maltreatment from the social system in which she functions that she should not tolerate.

It is within the context of both the general explanation of systems theory and more specific discussion of ecology theory that the discussion of African American families takes place. The framework of assets will also be discussed.

Family Developmental Assets

Hill (1972) (18) attributed five “original” characteristics to black families. These characteristics are as follows: strong achievement orientation, strong work orientation, flexible family roles, strong kinship bonds, and strong religious orientation. Additional attributes suggested at a later date are: extendedness, role flexibility, biculturalism, collectivism, and spirituality (19). Hill stated a two-fold definition of strengths as first, cultural assets that are
transmitted through socialization from generation to generation and are not merely adaptations or coping responses to contemporary racial or economic oppression (McDaniel, 1994) (20). Second, Hill stated that black family strengths are those traits that facilitate the ability of the family to meet the needs of its members and the demands made upon it by systems outside the family unit. They are determined by its ability to function in various domains.

In addition to family strengths, black family values have also been described. Sudarkasa (1996) (21) notes seven African American family values that, according to her, are the legacy of traditional African culture. These values are as follows: respect, responsibility, reciprocity, restraint, reverence, reason, and reconciliation. It is clear that both values and strengths are seen as assets of African American families.

Having described systems, in both a general and ecological sense, and having discussed the assets of African American families (strengths and values) the task of application remains. What is the relationship between African American families and health promotion? What role can and do the African American families play in health education, both within the family system and throughout the other systemic levels?

Family centered health care is becoming more popular in physical health care settings as health care providers have embraced a bio-psychosocial approach to physical illness. Within family medicine, the family systems approach is considered an important dimension to providing total care (Engel, 1980) (22). Positive health outcomes have been successfully linked to social support; families influence health beliefs and behaviors. According to Baquet & Gibbs (1992, pg. 111), “Blacks have less knowledge of health promotion and disease prevention measures than the general population”. This powerful observation is a challenge to those involved in female breast cancer education because the lack of knowledge often results in decreased participation in screening programs, failure to recognize early warning signs, and major delays in seeking diagnosis and treatment.

In a recent review of the role of the family in African American health, Myers, Echiverri & Odom (2004) (23) suggested (similar to Hill, Harrison, and Sudarkasa) that religiosity, flexibility in role function and extended/augmented family structures are protective resources. These protective resources are viewed as assets that help to counteract the known risk behaviors that contribute to high morbidity and excess health burdens of African American families. Examples of these health burdens are family poverty, single parent structure, chronic stress and unhealthy diets and obesity. Regardless of perceived family strengths or weaknesses family is usually the primary system of support and preferred intervention. Families, therefore, are examples of on-going, goal-seeking, self-regulatory social
systems that participate in a bi-directional flow of information, both within and outside the sub-system.

To summarize, it is proposed that by utilizing the assets of African American families, there will be more widespread knowledge of breast cancer education. Utilizing the assets of families also leads to utilizing the assets of communities - one of the foundational principles of community-based participatory research. According to Freeman, et al (1995) (24), community-based interventions have proven effective in eliminating disparities in screenings and improving patient survival.

Community-based Participatory Research (C-BPR)

Minkler & Wallerstein (2003) (25) described community-based participatory research as “an alternative orientation to inquiry that stresses community partnership and action for social change and reductions in health inequities as integral parts of the research enterprise” (p.1). According to Israel et al (1998) (26), the six basic characteristics that this type of qualitative field research must have are as follows.

1. It must be participatory in that community members both feel as though they are welcome and that they demonstrate active roles.

2. It is cooperative, meaning that both research interests and community interests are working together and not in conflict to one another.

3. Similarly, both those mainly interested in the research enterprise and those interested in the meaning and/or results that the research may have for the community should learn from one another’s areas of expertise.

4. C-BPR involves systems development and local community capacity building. It enhances already existing relationships among individuals as well as relationships among levels of systems. Stronger and deepened relationships support the community’s ability to replicate and expand on its pilot efforts.

5. Likewise, this development of both individuals and system levels is empowering to communities. When individuals and systems become more knowledgeable and gain more resources then they are more able to more intentionally and planfully develop their assets for greater gains.

6. Finally, good C-BPR achieves a balance between research and action. Specifically, research findings can serve as the basis for social action of the community’s choice.

The characteristics of cooperation, co-learning, systems development/local community capacity building led to the use of the PRECEDE-PROCEED model that both framed and organized the long term goals of the current
study. The adapted model for reducing breast cancer deaths is included in the Appendix A.

The premise of this model is simple: an educational diagnosis should precede an intervention plan. The process rests on the “principal of participation”. This is interpreted to mean that success in changing behaviors is greatly enhanced by the active and intentional participation of the participants (formerly described as subjects) in identifying and defining their own health priorities, goals, and solutions.

This model is a conceptual framework for practice and as yet is not at the level of theory. An overview of this model reveals a nine-step process. (Green & Kreuter, 1999) These steps are social, epidemiological, behavioral and environmental, educational and ecological, administrative and policy, implementation, process evaluation, impact evaluation, and outcome evaluation. The first five steps are those that precede the intervention and it complementary evaluation (Policy, Regulatory and Organization Constructs Educational and Environment Development) – proceed. The first two steps of (1) social assessment and (2) epidemiological assessment are the focus of the current study.

Cultural Competency

The aforementioned theoretical orientations cannot be implemented outside of the necessary condition of cultural competency. The most widely accepted description of cultural competency is that it is “A set of congruent behaviors, attitudes, and policies that come together in a system or agency or among professionals that enable effective interaction in a cross-cultural framework”. (Rorie, JA, Paine, LL & Barger, MK (1996, p.93). Three fundamental elements of cultural competency are self-awareness, knowledge of information specific to each culture, and skills that enable the individual to engage in successful interactions. (Cross, Bazron, Dennis & Issacs, 1989). Cultural competency includes economic differences, sexual orientation, and the social context in which individuals live. It is achieved by identifying and understanding the needs and help-seeking behaviors of individuals and families.

Operationally, cultural competence is the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, and practices and attitudes used in appropriate cultural settings to increase the quality of health care, thus producing better health outcomes. To be culturally competent, a person must demonstrate effectiveness in navigating through different cultural contexts. (Davis, 1997) For example, when working with women (and their families) of different ethnic, cultural, racial, and language backgrounds, each family is thought of as unique. In
addition, those differences are expected to enhance interactions as opposed to validating stereotypical thoughts and behaviors. (Lynch & Hanson, 1992). (31) According to Goode (2002) (32), cultural competency also involves working in conjunction with natural, informal support and helping networks within culturally diverse communities. Concurring with Minkler and Wallerstein, Goode thinks that engagement with the community of interest should result in the reciprocal transfer of knowledge and skills among all collaborators and partners. This conceptual model of family health education describes the relationship between the individual (facing a health challenge), the family assets, the role of culturally competent medical care, and the characteristics of C-BPR. This ecologically based model emphasizes the impact that C-BPR has on the various sub-systems as well as acknowledging the impact the individual has upon the entire system. Figure 1 illustrates the conceptual model.

**Figure 1 - Family Model of Health Education**

Purpose of the Study

The purpose of this study was to increase knowledge and understanding of breast cancer in African American women and their families. More specifically, this project investigated the relationship between knowledge and understanding of the causes and treatment of breast cancer using a community-based action research model of family health education.

This study had two goals: first, to address the general understanding that southern minority women have about breast cancer and second, to develop a model of family breast cancer education. The research questions were as follows. 1. To what extent will an action research intervention increase knowledge about the causes and treatment of breast cancer in women? 2. To what extent will an action research intervention increase willingness to talk with family members about breast cancer?

Methods

The research design for this study was a pre-experimental one-group pre-test-post-test (Kidder & Judd, 1986) (33). Convenience nonprobability sampling, particularly snowball and heterogeneity purposive nonprobability sampling were the methods of enrollment to this study. Trochim (2001) (34), in his discussion of sampling methods designates the following. Snowball (purposive non-probability sampling) is for use with hard-to-reach populations. In this study, minority women are identified as “the underserved”, based on prior empirical data regarding late presentation and later stage diagnosis. Heterogeneity (purposive non-probability sampling) is for use when one is intentional regarding some aspect of diversity or variety rather than representativeness.

To answer the research questions the authors implemented a three-stage action-research study. In the first stage, participants were assessed, via a survey, regarding their knowledge and understanding of the causes and treatment of breast cancer. In the second stage, an intervention, i.e., information about breast cancer was introduced to the participants. For the third stage, the authors re-assessed participants regarding their knowledge and understanding of the causes and treatment of breast cancer.

Participants

The plan to promote and give visibility to this project adhered to a recruitment process to address both the campus community as well as the city/county community. The campus community, i.e. university, was founded in 1892 as Slater Industrial Academy by Simon G. Atkins, an African American man. In 1925, the school became the first black institution in the United States to grant degrees in elementary teacher education. Winston-Salem
State University (WSSU) became a constituent member of the University of North Carolina state system in 1972. It currently offers 28 bachelor degrees and 5 master degrees. Enrollments are approximately 6,000 students of which about 5,000 are enrolled full-time. The ratio of female to male students is 2:1.

Announcements on the campus radio station helped to recruit participants as well as public service announcements on the “oldest radio station serving the black community”. Campus web email helped reach faculty, staff, and students who participated. Flyers distributed to dorms and meeting places of students and posters helped attract mostly students to the project.

Advertisements in the weekly minority targeted newspaper attracted participants from the city at-large. Principles of C-BPR were followed to enroll women from all socio-economic levels. To address their inclusion, community partners from the North Carolina Agricultural Extension Service were invited to be a part of the research team. The Extension Service workers distributed written materials that provided opportunities for the study to be introduced to several groups of low-income women; follow-up of the surveys was the responsibility of the Extension Services workers. Despite the best efforts of both the Extension Service workers and the other members of the research team, the low-income women, for the most part, did not complete both sets of surveys.

Procedures

This research project emanated from a public service center of a member institution of the state’s university system. The three-fold purposes of center were to (1) develop and replicate family support programs, (2) connect research, theory, and practice in education and outreach activities, and (3) inform practicing professional and policy makers regarding issues relative to improving practices and professional preparation. The visibility of the center as well as its reputation in the community served as a foundation for accessibility to prospective participants. Project members included center faculty, staff, and male and female undergraduate students.

After the IRB Committee of the university granted approval, the research team invited all minority women of the county to participate in the study. The PI met with African American and Hispanic community members who led or worked with community-based agencies and organizations. Research project team members contacted prospective participants in several ways: classroom presentation, drop-in (to the project office), and handed recruitment flyers out in face-to-face interactions. Participants who agreed to join the project each received a call from the Principal Investigator (PI) thanking them and offering to answer any questions they might have. Research team members recorded all vital contact data (home address, email, fax, cell phone numbers, pager numbers, etc.) using Microsoft Excel and Access software.
Successful completion of the project required that respondents complete and return two surveys. Upon completion of the first survey (Stage I), participants were eligible to go on to Stage II of the study (the intervention). Inquiries were mailed to 342 women who indicated through face-to-face contact, email, or by telephone that they were interested in participating in the research project. One hundred and fifty (150) women responded to the initial inquiry and were chosen to participate in the study. Of the 150 participants who were assessed in Stage I of the study, 117 returned their surveys. This represented a response rate of 78% for the Stage I portion of the study. Participants had approximately four weeks to engage in the intervention (Stage II) before participating in Stage III when they had up to six weeks to return the second survey. Of the 117 participants who completed the Stage III portion of the study, 97 completed the evaluations and were deemed completers of the study. Therefore, of the 117 participants who completed Stage III, 83% actually completed the entire process.

All members of the research team (PI, project coordinator, and three undergraduate assistants) made follow-up calls to encourage the return of the surveys for both Stages I and II. During the follow-up calls, the research team discussed the barriers that participants faced that hindered the completion of the surveys. In addition, at the end of the project, the research team publicly thanked the participants via an advertisement in the local African American weekly newspaper.

Data Analysis

Both quantitative and qualitative data were analyzed in this study. Surveys were scanned with Scantron equipment. The outputs of these data were Microsoft Excel spreadsheets. The spreadsheets were examined for errors by two research team members. Correct (clean) Excel data files were uploaded into the SPSS computer package and analyzed electronically by that package. Data were analyzed to produce both descriptive (demographic) and inferential (t-tests) statistical information. Qualitative data were recorded by hand.

Intervention

The single component of the intervention for this study consisted of a packet of selected information targeting African American women as well as supplemental material. This information addressed the two focal areas of knowledge and treatment of breast cancer. Some examples are as follows:

- Handouts and brochures from breast cancer organizations such as the American Cancer Society and The Susan G. Komen Breast Cancer Foundation.
Printouts from web urls regarding breast cancer
Printouts from urls specific to breast cancer about African American women
Web urls

Supplemental information included notifications about upcoming television specials (Lifetime Channel, etc.) and newly available videos. With the exception of the demographic information and the qualitative items, all of the items of the questionnaire mirrored the information packet.

Instrumentation
The 67-item questionnaire addressed several areas:

• Individual level information (8 items)
• Children and breast feeding (4)
• Individual and family history of breast cancer (5)
• Individual level of comfort in discussing breast cancer (1)
• Previous contact with breast cancer information (3)
• Knowledge (risks, causes, treatment) (42)
• Comfort level with knowledge of own diagnosis and sharing it with others (4)

Examples of questionnaire items are:

• “At what age did you have your first child”?
• “Did you breast-feed any of your children”?
• “Have you ever been diagnosed with breast cancer”?
• “Rate your overall comfort level in discussing breast cancer”.
• “Is this questionnaire your first contact with breast cancer information”?
• “Housework and gardening are exercises that will reduce breast cancer”.
• “Would you rather not know that you have breast cancer”?

Limitations of the Study
One limitation of this study was its reach. Although participants provided rich data regarding their knowledge about the causes and treatment of breast cancer and their willingness to talk with other family members, the researchers were aware that the participants did not represent the entire spectrum of families within southern African American communities. Many of the women who chose not to participate in the study were poorer women.
in the target area who might have become completers if the research team could have engaged them more intensely. Since many of these women were contacts of the Extension Services, home visits and other face-to-face interactions may have enhanced their participation.

Another limitation of the study is the researcher-created instrument that did not allow for any measure of reliability since it was created specifically for this project. In addition, there was not a pilot test of the instrument. However, three focus groups, i.e., panel of experts, contributed to the construct validity of the instrument. The three groups consisted of experts, such as agency cancer personnel and nurses. Two experts were also breast cancer survivors. The second group was survivors from both the campus community and the citywide community. The third - support-to-survivors group - was family members or friends who were either currently providing support or, in the past, provided support for a breast cancer patient. These experts provided resource material such as breast cancer questionnaires used with their patients and handouts from their agencies. Each group met separately and reviewed and discussed the readability of the drafted instrument, the number of questions, the breadth of questions, and the meaning of the questions.

**Results**

**Demographics**

The demographic variables from the surveys not related to cancer incidence were gender, education, marital status, income, age, ethnicity, and number of children. Demographics of the participants are as follows. The majority of the participants were female (94% female and 6% male). Almost all the participants described themselves as African American (99% African American; 1% Native American). The majority of the participants were middle aged or younger (42% younger than 30 years; 36% 31-50 years of age; 22% older than 50 years of age). Most of the participants had some college education (31% college students; 42% college graduate and less; 14% advanced degrees and education) and few had a high school education or less (13%). The participants varied in the amount of reported income (16% no report; 11% less than 10K; 22% 10-24,999K; 28% 25-49,999K; 16% 50-79,999K; 5% 75-99,999K; 2% 100+K).

Data regarding family variables reported by the participants were as follows. Married participants were in the minority: 29% married; 6% separated; 14% divorced; 7% widowed, and 44% never married. Most of the participants were parents (54%). A summary of these demographic variables is described in Table 1.
Table 1 - Demographic Description of Participants

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>DESCRIPTION</th>
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<tbody>
<tr>
<td>Sex</td>
<td>6% males</td>
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<tr>
<td></td>
<td>94% females</td>
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<tr>
<td>Education</td>
<td>13% high school graduate and less</td>
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<td></td>
<td>31% college students</td>
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<tr>
<td></td>
<td>42% college graduate and less</td>
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<td></td>
<td>14% advanced degrees and education</td>
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<tr>
<td>Marital Status</td>
<td>44% never married</td>
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<td></td>
<td>29% married</td>
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<td></td>
<td>6% separated</td>
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<tr>
<td></td>
<td>14% divorced</td>
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<tr>
<td></td>
<td>7% widowed</td>
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<tr>
<td>Income</td>
<td>16%, no report</td>
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<tr>
<td></td>
<td>11% &lt; 10K</td>
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<td></td>
<td>22% 10-24,999K</td>
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<td></td>
<td>28% 25-49,999K</td>
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<td>16% 50-79,999K</td>
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<td></td>
<td>2% 100+K</td>
</tr>
<tr>
<td>Age</td>
<td>42% &lt; 30 years of age</td>
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<tr>
<td></td>
<td>36% 31-50 years of age</td>
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<tr>
<td></td>
<td>22% &gt; 50+ years of age</td>
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<tr>
<td>Ethnicity</td>
<td>99% African American</td>
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<td></td>
<td>1% Native American</td>
</tr>
<tr>
<td>Number of Children</td>
<td>54% are parents</td>
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</table>

There were 42 items that designated at “knowledge” questions. These items were in the form of an objective paper-and-pencil test. Some items were true/false; some were multiple choice. The values assigned to the true/false items were 1 and 0 respectively. The multiple choice items were assigned numerical values that allowed the research team to assign values for the correct response and no value for an incorrect response.

The responses to the survey clearly addressed the research questions. Research Question 1 stated, “To what extent will an action research intervention increase knowledge about the causes and treatment of breast cancer in minority women”? The dependent sample t-test analysis of the self-administered paper-and-pencil survey indicated a significant increase (p<.001) in their knowledge, i.e., risks, causes, and treatment. It was hypothesized that the participants would know more about the causes and treatment of breast cancer (the 42 “knowledge” questions) at the end of the project, as
evidenced by their “scores” on the second survey. The mean score of the participants (n = 116) at Time 1/Stage 1 was 23.25. The mean score at Time 2/Stage 2 was 25.41. The hypothesis for Research Question 1 was supported.

Research Question 2 stated “to what extent will an action research intervention increase willingness to talk with family members about breast cancer”? These data are summarized in Table 3. There was not a significant increase (p<.304) in their willingness to talk with family members about the subject of breast cancer.

Responses to two items of the questionnaire demonstrated the role of African American family health promotion. The two items were: (1) “What would increase your comfort level in discussing breast cancer?” and (2) “If a friend of yours was invited to be a participant in this study, would you advise him or her to participate?” Responses to both questions provided rich data for further studies; responses were highly affirmative. Examples of responses to the item addressing comfort in discussing breast cancer are as follows:

- “Continuing education”
- “Probably with people associated closely with the disease, either just family members or interested in knowing”
- “I am comfortable with discussing breast cancer. I just need to know more myself so that I will be able to answer the questions on the previous page”
- “More information about the causes, signs, treatments and prevention of breast cancer”
- “Talking to someone who had breast cancer and survived it, instead of talking to someone who have (sic) never experienced it”
- “I have no problem talking (sic) it now. I feel, the more information about something, the more prepared you are”
- “More discussion”

Examples of the responses addressing advising a friend to participate in the study are as follows:

- “I think the questionnaire was very informative. Being a female you should know what might affect your body and your lifestyle”
- “It would have been nice to have some tentative timeline in the beginning of the process”
- “I am thankful for the opportunity afforded to participate. Hopefully, the study will help all of us and others to take cancer seriously”
- “Wonderful survey, but time consuming”
• “The information provided on breast cancer was very informative and helpful. I am still somewhat unclear as to whether or not Medicate (sic) pays for mammograms”

• “I consider the questionnaire to be informative and professional. Do it again in the future”

• “Thank you for including me in the breast cancer project. I learned much that I didn’t know and kept several of the sheets mailed with the second questionnaire. I’ve shared some of this new found info”

Table 2 – Hypothesis Tests

| Knowledge about Breast Cancer – dependent samples t-test |  |
|---|---|---|---|---|---|
| N | Mean Score Time 1 | Mean Score Time 2 | Degrees of Freedom | T-Score | Significance |
| 116 | 23.25 | 25.41 | 115 | 5.351 | 0.001 |

| Comfort Level in Discussing Breast Cancer – dependent samples t-test |  |
|---|---|---|---|---|---|
| N | Mean Score Time 1 | Mean Score Time 2 | Degrees of Freedom | T-Score | Significance |
| 110 | 1.73 | 1.65 | 109 | 1.033 | .304 |

Discussion

A family model of health education guided the research questions (a) to what extent will an action research intervention increase knowledge about the causes and treatment of breast cancer in minority women? (b) To what extent will an action research intervention increase willingness to talk with family members? This study investigated the degree of knowledge about the risks and treatment of breast cancer southern African American women and their families had. The participants in this study also responded to the degree of comfort in discussing breast cancer with others. Participant responses indicated the following. First, there was no significant difference at post intervention than at pre intervention in their feeling about “not knowing” if they had breast cancer. Second, there was no significant difference at post intervention than at pre intervention in their willingness to tell family members that they had a breast cancer diagnosis. There was, however, a significant increase at post intervention in their willingness to talk with family members about the subject of breast cancer. Fourth, at post intervention, their comfort level about discussing breast cancer increased as well as their
willingness to talk with others about their own (possible) positive diagnosis. Therefore, we infer that their increased comfort level and willingness to talk with others has a relationship to some degree of increased awareness.

Conclusions

This study is significant to the body of knowledge concerning female breast cancer for several reasons. One reason is that this study addresses both the contexts and relationships of breast cancer knowledge of risks and treatment. The family model of health education shifts the focus of breast cancer away from a diseased individual to an individual - with a disease - who is within several systems. Elements facilitating this shift are the approaches of community-based participatory research, cultural competency, and family assets.

Another reason this study is important is because it addresses awareness, i.e. heightening the sense of a dangerous situation regarding breast cancer; it addresses knowledge, i.e. “true facts” vs. misconceptions; and understanding, i.e. a synthesis of knowledge of and awareness that allows African women to share with others. Solid, effective models and processes; approaches and interventions that are theoretically sound and culturally congruent are useful in facilitating breast cancer education among African American women.

In addition, at the micro level, the findings of this study should assist clinicians and agencies in targeting their efforts and interventions much more precisely and effectively to influence the treatment of female breast cancer in their community. At the macro level, the Institute of Medicine (IOM) Report of 2003 (35) may be a useful resource to clinicians and agency personnel to help formulate policies that will more cogently address health disparities among underserved and minority populations. This is important because over half of the participants were over 31 years of age and 99% of the participants were women. Further item analyses and analysis of the qualitative data would greatly increase the understanding of breast cancer in African American women, in general, southern women, in particular, and other underserved populations. The family health education model can provide a different prism through which health professionals can begin to understand and address a wide range of health issues in many communities of color in the United States.
### Adapted PRECEDE Model for Reducing Breast Cancer Deaths

#### Health Problem
High Breast Cancer Morality by Minority Women

#### Selected Behavioral Cause of Health Problem
Late receipt of Breast Cancer Treatment

#### Factors Relating to Behavioral Cause

<table>
<thead>
<tr>
<th>Predisposing Factors</th>
<th>Enabling Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic Characteristics</td>
<td>Knowledge, Attitudes, &amp; Perception</td>
</tr>
<tr>
<td>Medically underserved population</td>
<td>Attitude re: early detection &amp; treatment</td>
</tr>
<tr>
<td>Low income</td>
<td>Knowledge of self-breast exam (SBE)</td>
</tr>
<tr>
<td>Ethnic minorities (2/3)</td>
<td>Knowledge of mammography</td>
</tr>
<tr>
<td>Low reading level/education</td>
<td>Perceived benefits of early detection &amp; intervention</td>
</tr>
<tr>
<td>Unemployment/underemployment</td>
<td>Perceived seriousness of illness</td>
</tr>
<tr>
<td>Single parents</td>
<td>Perceived susceptibility of illness</td>
</tr>
<tr>
<td>Religious</td>
<td>Fear of diagnosis, treatment &amp; perceived outcomes</td>
</tr>
<tr>
<td>Low preventive health measures (physical exams)</td>
<td></td>
</tr>
<tr>
<td>Excessive life burdens</td>
<td></td>
</tr>
</tbody>
</table>

#### Interventions
Predisposing, enabling, and reinforcing factors

#### Evaluation of Interventions

**Process Factors**
- Completion of Planned Activities
- Recruitment of residents
- Participation of residents

**Impact Factors**
- Short-term Goals
- Knowledge of self-breast exam
- Knowledge of breast cancer
- Knowledge of early detection interventions
- Intent to conduct self-breast exams
- Intent to get mammogram

**Outcome Factors**
- Long-term Goals
- Self-report of self-breast exam
- Self-report of mammogram
- Self-report of treatment for breast cancer
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