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Women Alive: Gathering Underserved Women Upstream For A Comprehensive Breast Health Program

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Abstract

A comprehensive breast health program, Women Alive, was developed and implemented by faculty and staff at a college of nursing. A community nursing practice model (CNPM) grounded in the values of respect, caring and wholeness guided the program. A foundation funded the program to provide breast health education, screening, mammography, and follow up services. Access for community outreaches at local churches encouraged participation of more than 1,300 Haitian and Hispanic women who received instruction on breast health. Women were referred for clinical breast exams, mammography, and care coordination according to guidelines. An inquiry focus group method was used to collect narratives of 26 women. Four themes: opening, discovery; empowerment and gratitude described the experiences of participation in an upstream approach to breast health.

Keywords: ethnic minority women, breast cancer, breast health, community nursing, and health promotion

Women Alive: Gathering Underserved Women Upstream For A Comprehensive Breast Health Program

"We didn't know what to do before but because of this program you showed us how to check our breasts every month. We made a lot of changes."

Introduction

This paper provides a description of a successful community nursing outreach program for breast health and the results of a qualitative study exploring the experience of participation in this outreach. The program, titled "Women Alive," was funded by a foundation and was designed and implemented by faculty and staff of a college of nursing in southeastern United States. Using an upstream approach to understand the social, political and cultural context of women's lives, over 1,300 underserved Haitian and Hispanic women participated in this community outreach. A sample of women (n=26) contributed narrative data that described their experience of participating in the program. The purpose of this study was to explore the usefulness of an upstream approach to breast health promotion for underserved woman.

Significance

The American Cancer Society[1] estimates that, in 2010, over 200,000 new cases of invasive breast cancer will be diagnosed and 40% of those women are expected to die. A higher rate of breast cancer among minority women is linked to the cultural, socio-economical, and political context of many ethnic groups living in the U.S.[2,3]

For many ethnic minority women in the community, the struggle to journey upstream for preventive health services is unimaginable. Haitian and Hispanic women represent a disproportionate number of ethnic minority women who do not receive adequate breast health care, and their cancer screening rates remain low.[4,5]

Early detection can reduce mortality yet ethnic minority women do not access breast health services with the same frequency as other women, and outcomes for detection, treatment, and survival reflect disparities.[6-8] Barriers to screening may range from lack of transportation to access health care to the failure of primary care providers to adhere to screening guidelines.[7-9] Although breast cancer is a priority agenda item for *Healthy People 2010*, and the National Cancer Institute specifically recognizes cancer health disparities in ethnic minorities as a burgeoning health issue, there is a lack of research specific to ethnic minority women.[7-9]

The stigmatization of breast cancer for women varies with race, culture and ethnicity. Further, the cultural beliefs of some African American, African Caribbean, and Hispanic women include fatalism (the inevitability of cancer in a lifetime) or that the treatments for cancer are more harmful and physically damaging than the cancer.[7,8] There exists a gap of knowledge related to Haitian women and breast cancer. Studies which include Haitian as the primary participants are scarce. This study helps close the gap.

Background

Faculty and staff from a university-affiliated Community Nursing Project (CNP) developed and implemented the Women Alive Program (WAP) for breast health. The intent of the WAP was to promote an upstream approach for ethnic minority women in underserved communities in a large county in the southeastern United States. Funding received from a foundation was used to design and implement a culturally sensitive program to reach women with limited access to health care. Faith communities opened their doors to the WAP and encouraged parishioners to gather and share their stories of caring for themselves and others.

The Community Nursing Project (CNP). The Community Nursing Project (CNP) provides health care for children and families throughout public schools clustered in underserved, ethnically and culturally diverse communities in a county of approximately 1.2 million persons. Faculty and students provide nursing and social services, which are directed to promote well-being and early intervention. The CNP was designed to demonstrate the integration of nursing practice, research, education, and development in community-based settings. Participatory-action approaches are employed throughout the CNP, and the inquiry group method[9] is used as the primary means of ongoing assessment. These approaches are grounded in the value of respect for the participants who are considered experts in their own care. The researchers and participants are partners in uncovering the meaning of the program.

Calls for nursing are expressions from the participants to be understood and to be cared for. These calls are indentified and used to create unique nursing responses with persons and groups in the various schools and communities. Collaboration is essential between communities, health care providers, foundations and governmental partners. Purposes, activities, and outcomes of the CNP are grounded in the philosophy and mission of the college of nursing and focus on nursing as nurturing the wholeness of persons and environment through caring.

Theoretical Approach

The specific theoretical perspective of the Community Nursing Practice Model [CNPM] grounded the design for the WAP. The CNPM is value based and offers the transcendent values of respect, caring, and wholeness of persons as an overarching guide for practice. The focus of nursing is nurturing the wholeness of persons and environments. Nursing is practiced within the ontext of the nursing situation, which is understood as the shared lived experience of caring between the nurse and the one nursed.

The CNPM depicted in Figure 1 is a vector image of an original hand-drawn watercolor of three concentric circles around a core. The perimeters of the core and concentric circles are fluid, allowing movement of persons and services from the core outward and from the concentric circles inward. The model illuminates the unique creation of nursing situations in the core and the seamless interconnections of relationships, collaborations, structures, and institutions within and across the concentric circles of empathetic concern. The CNPM guides the creative practice of nursing by integrating the values of respect, wholeness, and caring.

The CNPM supports an inquiry group method approach to gain insight into the calls for nursing from nursing situations. The inquiry group method[10] is defined as a route to know other questions through the use of focus groups. In-depth, open-ended discussions are carried out, during which a specific set of pre-determined issues are explored under the guidance of a facilitator. This method values each participant as an expert in the process and creates a deliberative democratic process of inclusion, dialogue and deliberation grounded in the values of respect, wholeness, and caring.

The Women Alive Program (WAP)

The breast health program outreach included the following key components: (1) breast health education, including breast self-exam (BSE) and risk factor reduction; (2) clinical breast examinations (CBE) by nursing faculty; (3) referral for mammograms; (4) case/care coordination for ongoing support of health practices or treatment; (5) selection and training of community members as *navigators* to assist with program design and treatment interventions; and (6) ongoing evaluation using inquiry group method.

Community outreaches were organized and supported by faculty, staff, clergy, and various community leaders. Access to the diverse communities was achieved initially by utilizing a local Haitian radio talk show. A group of faculty nurse practitioners was organized to participate as guest panelists on a popular radio program broadcast from a Haitian American radio station. The program had a large listening audience on Sunday afternoons and was conducted in Haitian Creole and French. The talk show host announced the program as a breast health initiative to invite community churches to participate in the outreaches. The faculty panel answered questions on the air related to breast cancer, screening protocols, and the services offered for women. Audience listeners were invited to contact faculty of the CNP for more information or to arrange an outreach. The response from church pastors was overwhelming. Forty-seven WAP outreaches were offered; 1,337 women participated, relationships were established with nine faith communities, eight county schools and district offices, and varied community sites such as Women's Clubs, and Housing Developments.

Most outreaches were advertised from churches, and participation was extended to all persons in the community. The educational component was instruction of breast self-exam (BSE) utilizing breast models and teaching materials such as videos and charts in Creole and Spanish. The educational programs were interactive with nursing students, and RNs and ARNPs engaged the audience to facilitate language and hands-on learning. Prior to each outreach, the site was surveyed for the possibilities of creating private examination areas to be set up at the outreach. These areas afforded the nurses and women an intimate atmosphere to promote authentic presence and to foster a caring environment. Several church

pastors made extraordinary efforts to provide portable exam rooms in church halls and hung with white shower curtains for privacy. The faculty and staff added to the nurturing environment with crisp sheets, soft background music and an infusion of natural calming oils. One pastor arranged the pews in the back of the church to accommodate women for learning BSE in a recumbent position. Each church had volunteer female parishioners to help with translations and organization of the outreach. A mammogram van was scheduled to be available on site at each outreach.

Women who met the ACS guidelines for screening mammography were provided with on site services. A CNP nurse or navigator accompanied women who required diagnostic mammography, ultrasound, or needle biopsy to referral agencies. The services were provided without charge if the women did not have insurance or stated they were unable to pay for such services. The desired impact on the target population was to empower the women with knowledge and confidence to access the health care system. The actual impact was to provide services for women who did not have the ability to access services due to lack of knowledge or financial resources.

Following is an overview of outcomes:

1. During the first quarter of the funding period, advanced registered practice nurses under the protocols of the county health department and supervising physician conducted breast examinations. Early on, the grantor decided to suspend the clinical breast examinations and directed efforts focus on teaching self-breast examinations.
2. Mammogram referrals (n=74) were generated and followed established program guidelines. The guidelines included: (a.) women over the age of 40, (b.) no previous mammogram, (c.) a palpable lump and (d.) had no health insurance or ability to pay.
3. The navigator concept was developed, a community member who would facilitate access to healthcare. A navigator, fluent in Haitian Creole and English, was hired and trained. A training manual was compiled and ongoing continuing training was provided. The navigators made all the difference in obtaining the care needed to follow through with breast health issues.
4. Care management was provided for the 74 women who needed mammograms. Each woman, due to language barriers and unfamiliarity with the health care system, was paired with a navigator to complete the care process in securing mammograms and follow-up care as needed. Many women needed just an hour to schedule a mammogram and learn about what to expect. However, for the four women who needed follow-up care, the navigators spent many hours to secure additional services, schedule and transport to tests or treatments and to

follow-up with received reports and recommendations. For one woman, the care management process required the navigator to make over 60 contacts with the client or healthcare providers.

5. Inquiry group method was used for assessment and evaluation. Twenty-four inquiry groups were conducted across the county to establish the program reflective of the community's hoped-for care, culturally appropriate care methods, and for evaluation of the care provided.

Method

Design

A qualitative descriptive design was used to collect and analyze data from women (n=26) who participated in the WAP. The inquiry group method guided the process of exploring what it was like to participate in the "Women Alive" breast health program. The method was expanded from a traditional concept of a focus group and was grounded in the values of respect and caring. The method was a good fit to assess and evaluate health programs in diverse communities. Data gathered through this method provided information about individual and collective strengths, resources, and needs. Inquiry group method guidelines include the following:

- Introduce self and participants
- Describe the purpose
- Establish the time frame and expectations
- Ensure confidentiality of all responses
- Review values of the CNPM model, e.g. co-participants are expert in self-care
- Ask the first question and invite the group to quietly reflect on the question
- Gather responses and thank each co-participant
- Reflect and summarize what was heard after the session and ask the group for confirmation or clarification

Ethical Considerations

Approval for conducting the study was obtained from the Institutional Review Board at the researchers' university. Informed consent was obtained from all co-participants prior to the study. The consent was available in English, Spanish and in Haitian Creole and trained language facilitators were available to read the consent if requested. Confidentiality was

maintained by the investigators. Transcriptions of the tape recordings and field notes use code names and have been stored in a secured area by the investigators. In addition to the ethical protocols, the investigators took the deliberate ethical stance of respect for each participant's voice.

Setting

Eight semi-structured inquiry groups took place at sites convenient for both the co-participants and researcher. Most groups were conducted in private offices in churches. The sites included five churches of various denominations and 3 school based wellness centers that were part of the service are of the CNP. The geographical locations included rural and urban communities. Some of the groups were conducted at night after church services to accommodate the women.

Participants

A snowball sample of 26 women between the ages of 35 to 50 consented to participate in the study. The sample size was not pre determined as all women were welcome to participate. Due to transportation issue and language barriers of the target population the intention of the researchers was to meet the needs of the women .The number of women in each group varied from one to 6 participants and this did not detract from the richness of the interview. Program navigators contacted several WAP co-participants by phone to inform them of the proposed inquiry group meetings. The co-participants spread the word to other women. Five of the co-participants spoke English, 16 spoke Haitian Creole and 5 spoke Spanish. Demographic information of the participants was limited to age and self identified culture/ethnicity. Due to the politically sensitive issues related to immigration women were not asked to identify their immigration status or place and type of employment. In the initial planning stages of the WAP church leaders implied that women may be reluctant to participate in a health promotion program if they were required to furnish 'papers' or documents that identified immigration status..

Procedures

The focus groups interviews were conducted in English, Spanish or Haitian Creole with the assistance of trained language facilitators in a group format that lasted about 30 minutes. Women who needed language clarification were informed to let the language facilitators know when translation was needed. Each focus group was audio tape recorded. The specific questions asked to all groups were:

1. What was it like for you to come to these education meetings with the nurses?
2. What was it like for you to learn how to examine your breasts?
3. How did the navigator help you get a mammogram, go to the health care provider, or go the hospital for care?

Before proceeding to the next question, the participants were asked if they had anything more to add. All of the women did not verbally respond to each question and some would nod to as a sign of agreement. Due to the complex nature of data collection with speakers of more than one language it was not possible to identify each speaker in the audio tapes.

The audio tapes were transcribed by the language facilitators immediately after the groups were conducted to verify any inconsistencies due to language with the participants. The researchers conducted a content analysis of the inquiry group data. Each researcher independently read the transcripts to identify key words, phrases, and significant statements. The researchers met on several occasions to compare and contrast their initial findings and then collaborated to reach a mutual consensus of the identification of the themes. Saturation was achieved when the researches mutually agreed that no new themes emerged. A reflexive approach was used to verify the meaning in context of the descriptors. To improve the credibility of the transcriptions, Haitian Creole interpreters were consulted to verify the data. Reflection on the data offered the opportunity to hear unique calls for nursing that gave direction for creation of nursing responses.

Analysis

The researchers conducted a content analysis of the inquiry group data. Each researcher independently read the transcripts to identify key words, phrases, and significant statements. The researchers met on several occasions to compare and contrast their initial findings and then collaborated to reach a mutual consensus of the identification of the themes. A reflexive approach was used to verify the meaning in context of the descriptors. To improve the credibility of the transcriptions, Haitian Creole interpreters were consulted to verify the data.

Findings

Four themes were identified from the data: *opening, discovery, empowerment*, and *gratitude*. The women's voices highlight the success of gathering for this upstream program. The discussion below offers direct quotes and interpretations of the women's' experiences.

Opening. This theme was brought forth by the women's description of being invited to participate and being welcomed into this program. They felt respected for who they were and what they brought to the process. Their comfort level allowed them to be open to share and to hear the health messages of self-care and breast care.

"When I learned the nurses were coming to our church, I didn't go to work that day so I could participate."
"A lot of women turn a deaf ear."
"Some are afraid of what they may find."
"I have a fear of being cut."
"Some women are really ashamed, that I know because I was like that. I don't want to be one of those women that have it metastasize and go through chemo and have my hair fall out. I am HIV and I would probably die."

Discovery. This theme emerged from the women's discussion of learning how to care for themselves and for others in their family and community. Women were eager to express how they embraced learning to care for themselves through self-discovery.

"I am very happy because I gave birth to 10 kids and I have never had anything like this, and now I found the program, I feel happy."
"I never thought about examining my breasts before, I learned the correct way and taught my daughter."
"We had a gentleman in our group. He said his wife never had a breast examination. He learned how to examine her breast and was taking it back home—he was an inspiration to me."
"It was my first time, at 42, to examine my breasts by hand."
"I thought just touching your breasts was examining your breast and it wasn't."
"I didn't know anything about this when I was in Haiti."

Empowerment. The women's sharing of how they were now caring for themselves illuminated this theme. They acknowledged the transformation of making healthy choices everyday and learning to live with the choices. Women felt enlightened by knowledge and empowered to change their attitudes and behaviors.

"We did not know what to do but because of the program it showed us how to check every month. It made a lot of changes, a lot of changes."
"I used to feel my doctor would always find everything that was wrong with me."

“I can promote it among my race of people because we know in the Black community it is almost unheard of women doing breast examinations at home.”
“We are doing something for our own health.”
“We used to neglect our breast, now we pay attention and keep our eyes close on them.”
“It is better to prevent than lament.”
“Before I didn’t care and now I do care.”

Gratitude. This theme flowed from the women’s voices of thankfulness to the nurses, to the program, and to God for being part of this experience set in the context of respect, caring, and wholeness of person. Expressions of gratitude were offered with a sense of relief and assurance of well-being.

“After my surgery, when I lay down sometimes, I am thinking, when will I have the opportunity to thank this group of nurses.”
“I hope you have the courage to continue doing this beautiful work because there is lots of people like me who don’t have insurance.”
“We thank the Lord. Thank you Jesus.”
“May God bless everyone for their hard work.”
“My last visit to my doctor, he told me that the lump I have is not cancer, thank you for helping me get the care I needed.”

The WAP was developed from the core values of respect, caring, and wholeness of others and offered the context for minority women:

1. To recognize an opening in the community to access breast health promotion;
2. To discover the process of self-care and the empowerment of knowledge; and
3. To express gratitude and hope.

This upstream approach focused on providing the participants access to compassionate, competent nursing care, developed from an understanding of the context of the women’s lives.

Discussion

The inquiry group method, defined as a route of knowing in which each person is an expert in the knowing of their experience, was used to design and evaluate the WAP. The value of respect was lived out by the nurse and co-participant as each listened and honored the other's views. Essential to this process was the nurses' commitment to create an environment of caring and respect where each feels safe to share. The descriptors in the data exemplified the reciprocity of respect and caring.

A major strength of this program was collaboration: funding from a foundation; development, implementation, and evaluation by a college of nursing's faculty and staff; and partnership with community churches and health care providers. The partnership with community churches was an essential component of the program. Faith-based health promotion initiatives have provided opportunities to access minority populations as churches are recognized as community institutions that have the ability to shape and influence social and religious norms in communities.[11-13] The role of the clergy may also have influenced positive attitudes toward health and well being through spiritual support and prayer. These establishments have a presence in the community and can provide opportunities for minority health promotion or for those persons who may be disenfranchised, marginalized or without access to care.[14,15] The CNPM guided the outreach program for more than 1,300 ethnic minority women and provided them with an opportunity to experience upstream breast health promotion.

Minority populations are frequently underserved, especially for upstream health promotion programs. A lack of participation, inaccessibility and language are limitations in conducting research. Although in this study the data collection method afforded the women an opportunity to voice their experiences, a limitation of this study was the difficulty of transcribing the audio taped data. Some of the recordings were simultaneous speeches of more than one speaker and in two languages.

The authors reflected on their divergent views about how to approach limitations in the preparation of the manuscript. A consensus was reached to include the section to inspire other nurse researchers who are intent on reducing the gap in knowledge about health promotion for minority women. Nurse researchers must persevere and demonstrate flexibility with data collection procedures that are complicated by language barriers and address these limitations with candor. More importantly, nurse researchers must express humility and collaborate with trusted community members/navigators as translators who understand the socio-cultural context of the data collection procedures.

The findings of this study offer a unique upstream approach to breast health education for minority women and the evidence of the usefulness of this approach to practice. The focus on the context of the women's lives provided the structure for the unfolding of this community based program in familiar and convenient locations, the women's churches, using language facilitators

The call to move health care into community settings challenges traditional hospital based practice courses and causes nursing faculty to ask "How should nurses be educated in community nursing?" How nurses should be educated to be authentically present for others to nurture and care." How should nurses be educated to care for minority groups of women? This study illuminates the usefulness of a community nursing practice model to not only guide practice but also to prepare students to provide nursing care in settings where people live, work, pray or play.

Conclusion

"We didn't know what to do before but because of this program you showed us how to check our breasts every month. We made a lot of changes." These words, introduced at the beginning of this paper, identify the values of caring, respect and wholeness of persons in gathering women upstream for health promotion activities. Grounded in upstream approaches to health promotion the WAP was developed from a particular theoretical perspective, the CNPM, and the transcendent values of caring, respect, and wholeness of persons. The faculty and staff were inspired to practice from these values and to reach out and through the concentric circles, strengthening and widening the web of relationships with colleagues, clients and community members.

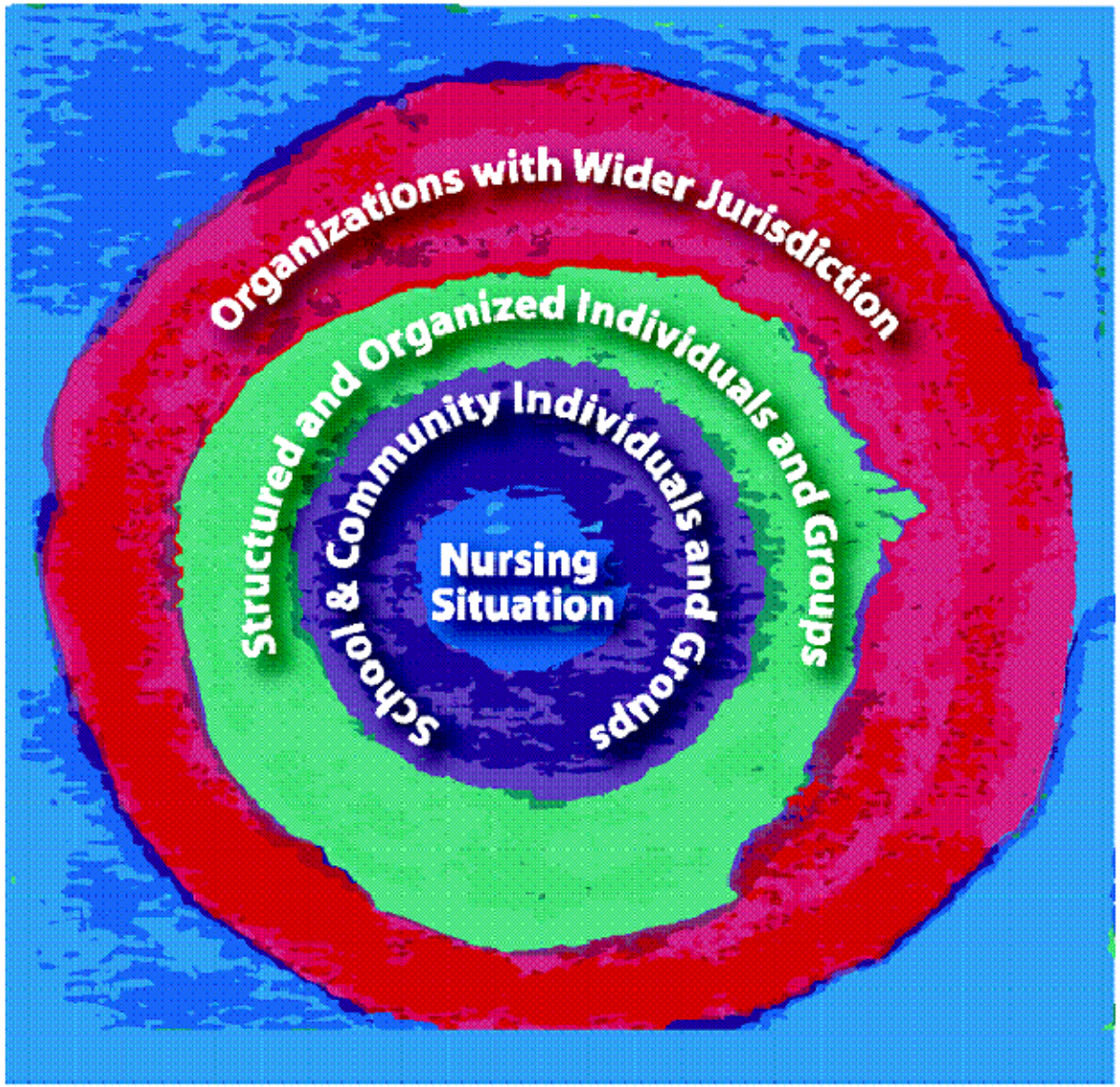
References

1. American Cancer Society(ACS). 2009-2010. *Breast cancer facts & figures*. Retrieved January20, 2011, http://www.cancer.org/downloads/STT/500809web.pdf.
2. Chu, K. C., Miller, B. A., & Springfield, S.A. (2007). Measures of racial/ethnic health disparities in cancer mortality rates and the influence of socioeconomic status. *Journal of the National Medical Association, 99*(10), 1092-1104.
3. Meade, C. D., Menard, J., Thervil, C. ,& Rivera, M. (2009). Addressing cancer disparities through community engagement: Improving breast health among Haitian women. *Oncology Nursing Forum, 36*(6), 716-722.
4. Centers for Disease Control and Prevention (CDC). (2010). *MMWR: Morbidity & Mortality Weekly Report, 59* (26), 813–816.

5. Masi, C. M., Blackman, D. J., & Peek, M. E. (2007). Interventions to enhance breast cancer screening, diagnosis, and treatment among racial and ethnic minority women. *Medical Care Research & Review, 64* (5), 195S-242.
6. Cronam, T. A., Villalta, I., Gottfried, E., Vaden, Y., Ribas, M., & Conway, T. L. (2008). Predictors of mammography screening among ethnically diverse low-income women. *Journal of Women's Health, 17* (4), 527–537.
7. Avis-Williams, A., Khoury, A., Lisoicz, N., & Graham-Kresege, S. (2009). Knowledge, attitudes, and practices of underserved women in the rural South toward breast cancer prevention and detection. *Family & Community Health, 32* (3), 238–246.
8. Spurlock, W. R., & Cullins, L. S. (2006). Cancer fatalism and breast cancer screening in African American women. *American Black Nursing Faculty Journal, 17* (1), 38–42.
9. Parker, M., Barry, C., & King, B. (2000). Use of inquiry method for assessment and evaluation in a school-based community nursing project. *Family & Community Health, 23* (2), 54–61.
10. Parker, 2000.
11. Baruth, M., Wilcox, S., Laken, M., Bopp, M., & Saunders, R. (2008). Implementation of a faith-based physical activity intervention: Insights from church directors. *Journal of Community Health, 33,* 304–312.
12. Frank, D., & Grubbs, L. (2008). A faith-based screening/education program for diabetes, CV, and stroke in rural African Americans. *Association of Black Nursing Faculty Journal, 19* (3), 96–101.
13. Watts, B. A., Merrell, J. Murphy, F., & Williams, A. (2004). Breast health information needs of women from minority ethnic groups. *Journal of Advanced Nursing, 47* (50), 526–535.
14. Kramish Campbell, M., Allicock, M., Hudson, M., Blakeney, N., Paxton, A., & Baskin, A. (2007). Church-based health promotion interventions: Evidence and lessons learned. *Annual Review of Public Health, 26*, 213–234.
15. Gullette, M. M., Brawley, O., Powe, B., & Mooney, K. (2009). Religiosity, spirituality, and cancer fatalism beliefs on delay in breast cancer diagnosis in African American women. *Journal of Religion and Health, 49* (1), 62–72.

Figure 1

The Community Nursing Practice Model: Concentric Circles of Empathetic Concern



The Community Nursing Practice Model: concentric circles of empathetic concern. Printed with permission from **the Florida Atlantic University.**