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Partners in health: Changing cancer screening disparity among underserved African American Women

Gloria Giarratano, *Celestine Carter*. **Journal of Multicultural Nursing & Health**. Chautauqua: Winter 2003.Vol.9, Iss. 1; pg. 40

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Subjects:	Breast cancer, African Americans, Women, Public health, Medical screening
Author(s):	Gloria Giarratano, Celestine Carter
Document types:	Feature
Publication title:	Journal of Multicultural Nursing & Health. Chautauqua: Winter 2003. Vol. 9, Iss. 1; pg. 40
Source type:	Periodical
ProQuest document ID:	327118571
Text Word Count	3918
Document URL:	http://proquest.umi.com/pqdweb?did=327118571&Fmt=4&clientId=30203&RQT=309&VName=PQD

Abstract (Document Summary)

Partners in Health: The Breast and Cervical Health Cooperative is a New Orleans based community health intervention program designed to increase access of underserved, African American women to life-saving early detection screening for breast and cervical cancer. Key to the program's success is its focus on culturally sensitive community education and outreach and helping women overcome barriers to screening. A dynamic group of culturally congruent community lay health educators were instrumental in changing women's knowledge and attitudes about cancer screening. The heart of their message is empowerment of women to take responsibility for their health through education, self-care practices, and annual screening. Faith-based and health care partnerships established community endorsement for the program and the community lay health educators helped women overcome mistrust and fear of the screening process.

Full Text (3918 words)

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[Headnote]

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KEY WORDS: Academic Partnerships; African American Women; Cancer; Health Disparity; Screenings.

Cultural and socio-economic barriers to mammography and cervical cancer screening have contributed to a distinct health disparity among African American women (Cooper, Hill, Powe, 2002; Lannin, Mathews, Mitchell & Swanson, 2002). It is well documented that breast and cervical cancer mortality rates are higher for African Americans than for European American women (American Cancer Society, 2002; U.S. Department of Health and Human Resources, 2000; National Institutes of Health, 1998). African American women are more likely to be diagnosed with cancer at a later stage and have a poorer

chance of survival. The five year survival rate for African American women diagnosed with breast cancer is 70% versus 85% for European American women. In Louisiana and the New Orleans region, cancer death rates exceed the rates of the nation, with marked disparity in the number of cancer deaths between African American and European women. African American women in the New Orleans region of Louisiana have a 1.5 times greater death rate due to breast cancer and a 4 times greater death rate due to cervical cancer compared to European American women in the region (National Cancer Institute, 1992-1999).

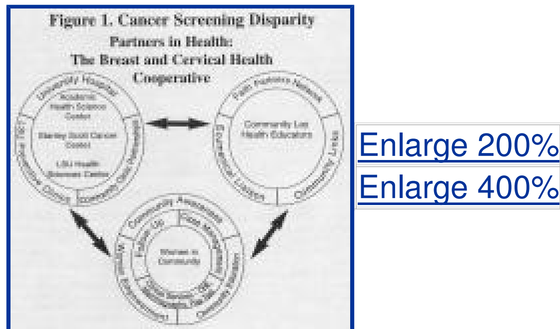

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Figure 1. Cancer Screening Disparity Partners in Health: The Breast and Cervical Health Cooperative

Lower breast and cervical cancer screening practices among African American women is one factor that is known to impact this situation. African American women are less likely to participate in routine health screening necessary for early diagnosis and treatment of cancer. Complex interacting factors result in barriers to African American women's participation in routine health screening practices (Kagawa-Singer, 2000). Among these variables are their cultural beliefs about health care, lifestyle, and cancer, their socioeconomic and historic circumstances, and their limited access to health care screening. As a result of these complex interactions, African American women have experienced disparities in cancer death rates and represent a medically underserved population that warrants targeting to improve cancer screening practices. The contextual and cultural nature of these barriers require specific interventions that will consider the multifaceted life situations and needs of African American women.

PROGRAM OVERVIEW

The program described in this article, Partners in Health: The Breast and Cervical Health Cooperative is a New Orleans based community health intervention program designed to increase access of underserved women to lifesaving early detection screening for breast and cervical cancer (Figure 1). The program was initiated in 1997 to fulfill the mission of the Louisiana State University Health Sciences Center (LSUHSC) Stanley S. Scott Cancer Center, which is to reduce the burden of cancer in underserved populations throughout the state. An initial pilot study highlighted the need for community health education among low-income women in New Orleans in order to enhance awareness of the purpose and importance of early detection practices for breast and cervical cancer.

The program is operated by the Stanley S. Scott Cancer Center, in collaboration with other parties, both within the academic health sciences center and community. Among those partnerships on the LSUHSC campus, include the School of Nursing, School of Medicine, Preventive Clinics, and University Hospital Mammography and Breast Center. Community sponsorship includes the Daughters of Charity Services of New Orleans Neighborhood Health Partnership (DCNHP), the Cancer Information Service of the National Cancer Institute, and the Louisiana Office of Public Health.

The Partners in Health (PIH) program sought to deliver culturally sensitive community education and outreach, access to screening, early detection services, and timely follow-up. African American and medically underserved women, who do not use such services regularly or at all, were targeted. The Partners in Health (PIH) program goals are consistent with the Centers for Disease Control and Prevention's (CDC, 2000) National Breast and Cervical Cancer Early Detection Program that aims to target underserved women for outreach, public education and improved access to screening and diagnostic services. The three main goals of the Partners in Health (PIH) project include:

* Increasing the participation of historically underserved and at-risk women in breast and cervical health programs by providing screening, health guidance, clinical tracking, case management, and referral services to eligible women.

* Strengthening and utilizing existing partnerships between community and professional groups and organizations, and

* Creating a team of trained Community Lay Health Educators (CLHEs) who can facilitate access to care and disseminate information about breast and cervical health.

The outreach component of the Partners in Health (PIH) program is implemented by Community Lay Health Educators (CLHEs). A project coordinator assists in training and overseeing the community lay health educators (CLHEs) and helps them to identify sites appropriate for educational outreach presentations. Educational outreach sites include worksites,

churches, community fairs, the waiting rooms of beauty shops, commodity distribution agencies, and occasionally in private homes. After the educational presentation, the program is designed for CLHEs to offer women, ages 40 years old and above, an opportunity to "sign-up" for the PIH program if they have no access to health care. The CLHEs provide the women with a dedicated clinic appointment for a clinical breast exam and Pap test screening at one of the collaborating clinics on the LSUHSC campus or in the community, and a mammogram appointment at University Hospital Mammography Center. The clinicians at the health clinics are primarily advanced practice nurses who are aware of the educational and cultural needs of the women. The clinical services for low-income women, over 50 years of age, with no insurance is made possible through CDC funding. Women under the age of 50 years, who have no access to services are referred to several community clinics that offer low-cost screening services. At the educational interventions, CLHEs conduct a pretest and post-test to evaluate learning. Afterwards, CLHEs provide follow-up phone calls to remind women of appointments or reschedule missed appointments. In three month and one year telephone follow-up interviews the CHLEs evaluate ongoing breast self-exam (BSE) practices. The program is also designed for one or two of the CLHEs to be present at the clinical service sites where pap and mammography screenings are done. CLHEs continue to teach and be present to support women during screening, and to provide continuity to the program outreach. Additionally the project coordinator is informed of abnormal reports so that she can provide case management that assists the clinical sites to facilitate further diagnostic appointments and/or timely interventions.

PROGRAM OUTCOMES:

Since 1997, the Partners in Health program has provided to over 15,000 medically needy and underserved women free mammograms, Pap smears, clinical breast examinations and education. Analysis of the program objective, which projected that over a two-year period of time, 950 participants would receive a screening mammogram, identified that 1,895 women actually received the service, which exceeded the target by nearly 200%. Outcomes related to another program objective demonstrated that the average improvement in knowledge from pre-test to post-test (6 months later) concerning myths about breast and cervical cancer screening was 54%. Also, 88% of the women who could be contacted and screened in one-year follow-up telephone calls reported practicing monthly breast self-examinations. Many women, unfortunately, were lost to phone follow-up one year later due to the phone service being disconnected or women moving without forwarding phone service. The average show rate for clients scheduled for mammogram screening over a 2 year period of time was 64%. These data continue to demonstrate that more work is needed in finding strategies to help clients to overcome their screening barriers. Finally, due to the program's collaborative approach to early detection, follow-up, and intensive case management, only seven clients out of 260 over the past two years were lost for follow-up procedures after their initial screening reports warranted additional evaluation. The women were unable to be followed due either to the transient nature of the women or because of erroneous information provided concerning addresses and/or phone numbers.

RECIPE FOR SUCCESS:

Partnerships, Spirituality, Cultural

Congruence, Trust:

Qualitative evaluation focus groups were conducted with the Community Lay Health Educators (CLHEs) and women-clients by an independent researcher. The program co-directors also conducted ongoing evaluation of the program. Based on this focus group and evaluation data, four program strengths have emerged as primary to the success of the Partners in Health (PIH) program. These four strengths include development of partnerships between the health care systems and the community, and the integration of spirituality, cultural congruence, and trust building within the program.

A major element of the Partners in Health program that was key to its success in improving women's access to education and screening services was forming partnerships among multiple health care professional organizations, providers, and the community served. These community partnerships included African American churches (Faith Partners Network), community leaders, as well as the women served (See Figure 1). The program was designed to facilitate community commitment and ownership of the program by a network of African American churches and utilization of community lay health educators (CLHEs) from within the community for outreach efforts. Active involvement by the community has been recognized as a successful strategy to facilitate health screening where cultural barriers exist (Clover, Redman, Forbes, et al., 1996; Fletcher, Harris, Gonzalez, et al., 1993; Hyatt, Pasick, Stewart, 2001).

The community endorsement for the PIH Program has been a strong foundation for its success. The African-Faith based organizations and community leaders work closely with the PIH Program Coordinator and CHLEs. The PIH program also provides an Ecumenical Liaison, a female minister, who is a spiritual advisor to program participants, the CLHEs and acts as a faith-based consultant to the program. The Ecumenical Liaison minister also coordinates health fairs and other outreach activities with churches in the target zip-code areas. In addition, all CLHEs are active in their churches and appreciate the physical, emotional, and spiritual needs of the whole person. Many program participants are active churchgoers who were receptive to education concerning a holistic approach to health. Embedded in this spiritual message is also a message of woman-self-worth and empowerment, which is applicable to all women served.

The positive impact of spirituality on the program is a reflection on the cultural value of spirituality among African Americans.

Since slavery, religion has been an enormous component of African-American culture. Slaves used songs and prayer as a means of communication and hope for freedom. The church remains one of the strongest social influences in decisions made by African-Americans. Davis (1994) emphasized that minorities pay close attention to messages that are provided by the minister and other churchgoers concerning matters such as healthcare, money and personal/family affairs.

The community lay health educators (CLHEs) developed a community amongst themselves and established approved mores for the group. As a faith-based group, spiritual communications are accepted as the norm. Monthly meetings start with prayer, whether the setting is in a nearby church or in a private conference room at the Stanley Scott Cancer Center. Members may share personal or family concerns they want others to know and pray about. Bringing prayer into the secular academic health sciences center blurs the public and private domains and represents the faith-based emphasis of the program. The CLHEs integrate the private and public domains to fulfill the mission of the program that, to them, requires spiritual intervention to empower women.

The community lay health educators (CLHEs), themselves, emerged as the primary link that bridged the cultural and socioeconomic barriers to educate and recruit underserved African American women into the program. This dynamic group of 8-12 African American women reached the community through a message of spirituality and empowerment of women and a sense of responsibility for their health through education, self-care practices, and annual screening. A core curriculum was developed to educate the CLHEs and for their use as a guide for the outreach educational sessions. This guide included usual information such as statistical data, cancer prevention education (diet, exercise, breast self exam), reproductive health education, routine health care screening recommendations, explanations of procedures and model demonstrations. The CLHEs reviewed this core curriculum, integrated and transformed the message in ways that acknowledged the context of health care and life style experiences of African American women. Establishment of a common cultural identity with the women allowed the CLHEs to reach and earn the trust of African American women. The contextual nature of the educational sessions reflected the unique language and meanings of cancer from the perspective of the urban African American women from which the CLHEs and the program participants are members. Such cultural and linquistic competence may be defined as the ability of the CHLEs and the health care system to respond effectively to the cultural and linquistic needs brought by the women-clients to the health care encounter (National Standards on Culturally and Linguistically Appropriate Services, 2001).

As a result of their relationship with the women, the CHLEs are able to develop a level of trust that facilitates open communication about many fears, myths, and injustices that relate to health care issues. Often times the women express fear and mistrust of the health care system, unique to the African American experience.

There is extensive history that explains why African-Americans are fearful and distrustful of health care providers (Rimer, Conway, Lyna, Woods-Powell, Tessaro, Yarnall, Rakowski & Barber, 1996). Many African-American people fear routine medical or surgical procedures, believing they subject themselves to pain, suffering and being a victim of experimentation. African-Americans also fear that their bodies will be mutilated, and refuse to consent for autopsies. These fears may have spawn from the antebellum period when African-Americans were first used for medical experimentation. "Slaves found themselves as subjects of medical experiments because physicians needed bodies and because the state considered slaves as property, and denied them the legal right to refuse to participate" (Gamble, 1997, p. 1774).

Though many of these accounts are based on folklore, the most reliable evidence of ethical misconduct in human research, and government abuse of African-Americans evolved from the Tuskegee Syphilis study, which was conducted over a forty-year period of time (1932 to 1972). In this study, approximately 400 African-American sharecroppers from Macon County, Alabama were deprived of effective treatment for advanced syphilis as part of a United States Public Health Service experimental study designed to determine how syphilis affected Blacks as compared to Caucasian people. The fear and stigma generated from the Tuskegee Syphilis study remains widespread throughout the United States, especially in the deep south, and has made it difficult for African-Americans to trust their health care providers (http://www.med.virginia.edu/hs-library/historical/apology/report.html).

Cultural mistrust of the health care system was evident from African American women's initial responses to the educational component of the program. Examples of cultural mistrust that evolved during educational sessions, screening and telephone interactions among African American female clients, CLHEs and health care providers is best depicted by actual statements from clients.

* A 44 year old client stated: "Gull please! I'm not going down there to Chatty Hospital and let them people use me as no guinea pig. When the doctors do a Pap smear, they put something on that stick that they put inside ya that make ya come down with cancer. "

* A 50 year old client stated: "After you get a test done all they want to do is to cut on you. Most of the time, you don't know if they are telling the truth or not. Once the doctor cuts a person open, cancer starts to spread all over the person's body. "

* A 72 year old client stated to a CLHE: "I will go to the clinic if you come with me. That might keep them people in the clinic from treating me so bad. I don't like being talked to and handled like a dog when I go to the Doctor for a check-up. That's why I don't like to go. I think that your program is a God-sent one. I feel comfortable talking to you, and believe that you won't

let them people experiment on me. "

* A 22 year old client stated: Child, you gotta die from something! More of us get cancer than white folks so I pray and ask God to keep me from getting cancer, or just deal with it if I do get it. I don't want them people using me as no guinea pig. They cut you open for one thing and before you know it you ain't got nothing down there, clean as a whistle, and ain't good for nothing in bed cause they be done took out all your stuff."

Myths about cancer are also commonplace and reflect the fatalist meanings of cancer held by many African American women. Myths have been documented by other researchers and clinicians working with African American women (Adams, Becker, & Colbert, 2001; Moore, 2001). The following statements represent misinformation and myths about cancer screening and disease management that were experienced by African American women in the PIH program that must be overcome by the program:

* A 52 year old client stated: "Those x-ray machines are full of radiation that leads to breast cancer. Anyhow, my boobs are too small to get cancer. "

* A 65 year old client stated: "My Grandma told me that if I let that mammogram machine squeeze and bruise my tiddies, I will come down with cancer in the long-run."

* A 28 year old client stated: "When the Doctor cuts you open, it causes cancer to be exposed to air and spread all over your body and causes you to die."

* A 56 year old client stated: "Once you come down with cancer, you just might as well just pray and ask the lord for strength and prepare to die soon, cause the Doctors can't do nothing for you no how."

* A 68 year old client stated: "I been here from Trinidad for 6 years now. I ain't been to none of them doctors here. I met a woman 3 years ago who had one of them Pap things done and it started her to bleeding and she came down with cancer and died a few months later."

* A 50 year old client stated: "My mom's sister died from breast cancer. About a year before she died, she had a mammogram done. My aunt said that the mammogram gadget mashed down on her breast so hard it felt like one of those wringers from the old types of washing machines. That gadget caused bruising of her breasts, which lead to cancer in one of her breast. The Doctors did surgery on her and cut her breast off, and gave her some poison medicine that made her get a bad rash all over her body and all of her hair fell out and she still died from it. I'm just gonna trust in the Lord to help me if I get sick. I don't want to go through all of that pain and suffering my aunt went through with her cancer, and died, anyhow."

* A 48 year old client stated: "I been through menopause and I ain't done the wild thing in 7 years, so I can't get cancer in my tiddies neither my cuccie."

The CHLEs acknowledge and confront the cultural myths on an ongoing basis as they perform their mission. Through cultural and linguistic competence they are uniquely qualified to debunk the myths and help women come to new understanding of their bodies and the need for preventive health care practices. By developing trust with African American women, the Partners in Health (PIH) program bridges the gap between the academic health sciences center, its health care services, and the women who need health education and breast and cervical cancer screening in the community. This program has demonstrated that by utilizing culturally congruent women (CLHEs) as educators and navigators in their own neighborhoods, churches, beauty parlors and homes, barriers of fear and distrust of the medical community, which keeps underserved women from using life-saving health screenings, can be overcome.

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