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Community Based Participatory Research

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Abstract

Community Based Participatory Research (CBPR) is increasingly used as an approach to build community health and welfare with the use of research partnerships linking communities and academic researchers. CBPR promotes collaborative processes, resulting in programs that facilitate full and equal participation by all research representatives; these include academic partners, community members, and community organizational agents. Woman of Faith and Hope (WOFAH) is used as an example of a non-profit organization that seeks to mitigate the burden of breast cancer in the community it serves in Northwest Philadelphia. WOFAH is an essential component for providing needed educational information and referrals for breast health screening and treatment in this primarily African American community. La Salle University is the academic partner working to help evaluate the use of evidence-based programming and its ability to meet the needs of community members. The need for continued funding to support WOFAH program initiatives is vital; grant providers require information that demonstrates the use of evidence-based programming.

Keywords: community-based participatory research, health disparities, African American breast cancer incidence, evidence-based programs, advanced practice public health nurse

Community Based Participatory Research

Introduction

Community-based participatory research (CBPR) has gained momentum within the last two decades as a process for academic researchers to work together with community partners to increase understanding of topics of concern in underserved populations (Savage et al., 2006; Wallerstein & Duran, 2006). CBPR is a collaborative method allowing all partners to have equal involvement in the research process while identifying the specific asset that each collaborator brings to the process. The ultimate goal works to create changes in the community that come out of social change targeting progress in community health and eradicating health disparities (U.S. Department of Health & Human Services, 2012; Wallerstein & Duran, 2006). This method promotes greater involvement on the part of residents in the community along the research continuum, allowing for improvement in understanding significance and knowledge of research for community participants, organizational agents, and academic researchers (Hergenrather, Geishecker, McGuire-Kuletz, Gitlin, & Rhodes, 2010; U.S.

Department of Health & Human Services, 2012).

Community based organizations (CBO's) often partner with academic institutions to carry out research and assist with transferring new knowledge to constituents in the community (Ramanadhan et al., 2012). Evidence-based practice (EBP) utilizes proven scientific practice to provide professional, expert care that is culturally sensitive and aligns with individual needs and preferences. Community-based research provides opportunity for CBO's to play a vital part in the provision of EBP. Community-based organizations rely on funding from both private and government sources. Federal agencies expect programs to be evidence-based. In the Center for Disease Control and Prevention's discussion of the "The American Recovery and Reinvestment Act of 2009", it reports that the money allocated for programs must be used for "evidence-based clinical and community-based prevention and wellness strategies" (Jacobs, Jones, Gabella, Spring, & Brownson, 2012).

CBPR partners include outsiders to the community under study, such as academic researchers. Community members incorporate the population whose needs are being researched; the idea of community is broad-based and encompasses individuals with shared interests, norms and values, and similar sense of identity. Community members can provide reliable information on norms, local perspectives and valuable ways to conduct the research process. The third partner in CBPR is the organizational representative or "community gatekeeper" (Hergenrather et al., 2010). This role is essential for giving academic partners access to constituents in the community as well as ensuring adherence to research objectives, methods and protection of the community under research. Organizational representatives are vital for promoting and continuing lasting research collaborations.

Partnership principals are important for launching and developing CBPR opportunities. New research relationships take time to establish and form trusting, multidirectional connections and bonds with all collaborators. The following are illustrations of principles of CBPR partnerships: 1) establishment of mutual respect and authenticity, 2) creation and use of formal and informal partnership networks, 3) having clear and concise communication processes, 4) mutual identification of roles and procedures, 5) using each partners strengths and talents, 6) forming an agreement on the purpose and aims of research, 7) maintaining frequent interactive viewpoints, 8) equitable sharing of power and resources, 9) fair acknowledgment of achievements, 10) confronting difficulties as a group, 11) creation and participation with associations built outside of the group, 12) using available environmental resources

to promote group aims, 13) having ownership of collaborative process and outcomes, and

14) communicating outcomes and results to academic groups, constituents, and creators of policy (Hergenrather et al., 2010). These principles highlight the importance of maintaining the tenets of partnership, creation of trust, and cooperation during the CBPR process.

Data Collection

The aggregate population under study includes the members belonging to, and the individuals that connect with the non-profit organization, Women of Faith and Hope (WOFAH). WOFAH exists to provide information, education and spiritual and emotional support to assist women with concerns related to breast cancer. These efforts strive to lower the mortality rate from this disease through screening and early detection (Women of Faith and Hope, Inc., 2012). WOFAH reaches out to all individuals in need of assistance with a primary focus directed toward African-American females residing in the Northwest area of Philadelphia. Opportunities for gathering are open to all ethnic and racial backgrounds; the organization targets low-income African-American women who suffer higher rates of mortality from breast cancer. The majority of program participants are between ages 35 - 75 years; attention is directed to those who are under-insured or uninsured.

Self-help group meetings are held monthly at four locations in the Philadelphia area, providing opportunities for women to attend programs at a variety of sites at different times and on different days of the week. Locations include churches and a community center that are easily accessible to attendees. An additional facility holds meetings on a quarterly schedule. Data is collected from Self-help group meetings with the use of a questionnaire that provides quantitative as well as qualitative information. Quantitative data provides information on participant referral sources, reason for attending, first time attendance status, number of times for past participation, and category (survivor, relative or caregiver). Qualitative data pulls information on participant recommendation for speaker or topic, suggestions to improve programs, session information that was most helpful, and open-ended comments (Appendix A).

Information gleaned from the questionnaire reveals that many of the participants are breast cancer survivors or family members of affected females. The top three reasons for attending programs are for information, support, and membership in WOFAH. A majority have attended group 1-5 meetings in the past. More than half of program attendees are cancer survivors, the second largest group report being caregivers with many in both categories. Self-help meeting participants also document the importance of enrichment and spiritual sustenance received as an integral part of each event (Appendix B).

Review of program evaluation forms completed during 2011-2012 provides evidence of inconsistency in the number of forms that were filled out by participants. Self-help group meetings held during October were celebratory events for breast cancer awareness and questionnaires were not distributed. Meetings were not

held during some months due to program leader unavailability for personal reasons or inclement weather. In some cases evaluation forms were not given out due to unknown factors.

Women often connect with WOFAH at outreach events and receive direction and referrals for breast health screening tests. A Referral Services form is completed by staff or volunteers; this form documents demographics, insurance status, referral source and outcome, mammogram history, current symptoms, and family history. Follow-up communication documents whether individuals have received necessary tests. If testing has not been completed, women are given encouragement and reminders on the importance of self care strategies to mitigate the development of possible disease (Appendix C).

Health Issue of Concern

Community based participatory research was chosen to assess this aggregate due to the positive impact that this process has on decreasing health disparities in underserved and minority populations. Racial disparities are significant with regard to breast cancer incidence and outcomes in African American women (Sail, Franzini, Lairson, & Du, 2012). Although African American females have a lower incidence of breast cancer diagnoses, they have increased rates of mortality compared to White women (American Cancer Society, 2012; National Cancer Institute, 2008). Despite overall improvements in mortality from cancer, higher death rates from cancer in African American women have been influenced by increases due to breast cancer. Reasons that are important in the increased mortality rate for this population involve issues with accessing and using screening measures and therapy, as well as higher risk tumor biology with poorer prognostic factors (American Cancer Society, 2012). Just half (51%) of African American women have local stage disease at diagnosis compared with 61 % of White women. This delay in diagnosis is attributed to lower use of, and greater duration between mammograms, as well as poorer follow-up of abnormal findings. Research has linked issues related to socioeconomic status with differences in the biology of breast cancer; women living in greater poverty have an increased propensity of developing estrogen-receptor negative tumors. Financial instability may affect pathology of breast cancer and genetic traits due to the influence of diet, activity, environment, and reproductive patterns (American Cancer Society, 2012).

CBPR is an effective way to link the academic researcher, La Salle University, with the community partner, WOFAH, and members of the community served by WOFAH. This collaborative relationship brings about change by increasing access, support and educational efforts to improve screening and referral for quality health care treatment. CBPR uses the assets and resources of the community partner organization and community members; these include program participants, facilities where programs and events occur, staff and volunteers, WOFAH website, referral partners, and written literature. The process of CBPR also benefits from the inside knowledge of WOFAH's President and Founder, Novella Lyons (Savage et al., 2006). Ms. Lyons has a unique perspective and comprehension of the understanding, barriers and fears faced by women in the Northwestern Philadelphia community targeted by the organization; she brings forth the silence that permeates this group with the need to encourage women to actively

participate in screening and use of medical care to decrease delays in diagnosis and improve survival from breast cancer (N. Lyons, personal communication, November 2, 2012). CBPR brings the resources of WOFAH together with women in the community through educational and outreach programs that provide information, guidance, physical, emotional, social, and spiritual support. WOFAH provides La Salle University, the academic partner, with access to the non-profit group's participants. The academic partner is assisting with research and assessment of program evaluations to determine the effect of evidence based programming on outcome measures. The effect of program activities is measured with evidence of improved understanding of health issues related to cancer prevention and care, better identification of methods to benefit health promotion and cancer prevention, and improved support for social and emotional issues for those in need (Bicknell, 2011). Members of the academic team from La Salle University are also providing expertise for grant writing to assist with obtaining grant funding opportunities.

Utility of Model for Advanced Practice Public Health Nurses

The CBPR model is an effective tool for the Advanced Practice Public Health Nurse (APPHN) to create and build partnerships and enhance distribution of evidence-based practice. Research promotes teamwork and is more likely to result in successful outcomes for translating EBP's into application in the community setting. This focus helps the end-user or community partner with process-improvement strategies to control, create and make use of resources that will help with initiatives for problem-solving (Ramanadhan et al., 2012). The APPHN position incorporates eight principals that are fundamental in this role: 1) client or group as the population, 2) duty to care for the group in its entirety as an equal, 3) operating in partnership with groups and organizations, 4) focus on primary prevention, 5) find methods to create a setting to help populations succeed, 6) find and assist all persons who may be helped by identified services, 7) make the best use of resources to promote inclusivity for health improvement, and 8) collaborate with a network of professionals, populations, organizations to advance and care for population's health (Levin et al., 2008). These principals are also integral to the CBPR process with the focus on building collaborative relationships and community participation to reach the goal of developing greater understanding of the population's needs (Savage et al., 2006).

A significant challenge for the APPHN occurs when unmatched goals result from differences in characteristics of the population under research, staff, resources of the organization, and unique issues in the community. Barriers to CBPR may occur with limited resources, difficulties with program modification, and organizational philosophy. Lack of sufficient staff, burdensome documentation and reporting requirements, and insufficient knowledge of the grant writing process can hinder the research process. Programs must be adapted to be culturally relevant with language and processes that fit with community norms and are understood by constituents in the group. Motivation of an organization to use CBPR for disseminating evidence-based practice methods is another limitation; adaptation of new processes requires change in culture and practice (Ramanadhan et al., 2012).

Challenges that have been encountered with the collaboration with WOFAH include having limited resources of staff; Novella Lyons is the only paid staff member and the organization relies primarily on volunteers for providing outreach and educational programs. Financial support comes from private donations, corporate and foundation grants, and non-profit community organizations such as the American Cancer Society. The process for writing and submitting grant requests is hampered by lack of sufficient staff that can carry out the grant application process. An additional challenge with CBPR includes the commitment of time for developing and renegotiating relationships between members, training of collaborators and data analysis (Savage et al., 2006).

Conclusion

Community Based Participatory Research provides a unique opportunity for collaboration between academic researchers, community organizations and community members. All members of the research team can work together to address public health issues of concern that are important to the population under study. Building relationships that establish trust between collaborators, increasing knowledge of partner needs and attitudes, and sharing life experiences enables underserved communities to make progress and promote changes for improvement in use of positive health behaviors that will benefit long-term health outcomes.

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