



HHS Public Access

Author manuscript

J Cancer Educ. Author manuscript; available in PMC 2016 December 01.

Published in final edited form as:

J Cancer Educ. 2015 December ; 30(4): 616–622. doi:10.1007/s13187-014-0746-3.

A community coalition to address cancer disparities: Transitions, successes and challenges

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Abstract

Community-based participatory (CBP) strategies are considered important to efforts to eliminate disparities. This paper outlines how the Program for the Elimination of Cancer Disparities

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Conflict of Interest

The authors have no conflicts of interest to declare.

(PECaD) uses CBP strategies as a part of a long-term cancer education, prevention and control strategy in an urban community. Community partnerships have proved to be vital resources to inform PECaD's agenda and the research practice of academic partners. We begin with a description of PECaD governance and partnership structures. The paper then describes programmatic activities and successes, including efforts to monitor clinical trials, deployment of mammography resources, anti-smoking, prostate and colorectal cancer (CRC) screening education. The influence of changes in funding priorities, preventive screening policy, and community partner development on the partnership process over time is discussed. PECaD community partners have grown and expanded beyond the Program's mission and developed additional partnerships, resulting in a reevaluation of relationships. The impact of these external and internal changes and pressures on the partnerships are noted. The evolution of the evaluation process and what it has revealed about needed improvements in PECaD activities and operations is presented. A summary of the lessons learned and their implications for CBP practice are provided.

Keywords

Community Based Participatory Research; cancer prevention and control; health education; health disparities

Introduction

Community engagement requires respect for the values of the community and the value of incorporating community perspectives and insights into research and interventions [1]. A community engagement approach promotes changes in programs and policies designed to improve health through mobilization and organization of resources, individuals and institutions [2, 3, 4]. Community-based participatory processes have been identified as potential methods to address disparities [5, 6, 7] due to their emphasis on partnership with and participation by the communities, from conceptualization of the ideas and methods, to implementation of services and activities and interpretation and dissemination of results [4, 8]. This approach to disparities reduction is believed to improve community acceptance of and implementation of cancer prevention activities, including screening [5,7].

Proponents of CBP based efforts suggest that the process achieves its aims through principles focused on bringing together researchers, practitioners and communities to establish trust, share power, foster co-learning, enhance strengths and resources, build capacity, and examine and address community-identified needs and health problems [3,4]. The success of CBP approaches depends on trust and rapport with community members and strong community-practitioner/ researcher relationships [2]. In addition, CBP's ability to generate novel partnerships may contribute to its value in the reduction of health disparities [9].

Examinations of CBP efforts suggest that institutional and faculty commitment to engagement principles, flexible and inclusive governance structures and strategies to educate community members must be developed to assure that the barriers to CBP frequently identified in the literature do not inhibit success [10]. The development of the relationships,

trust and rapport required for CBP can be inhibited by imbalances in power and knowledge that often exist among practitioners, researchers and the community members engaged in the CBP effort [10]. In addition, equal participation in efforts seems particularly difficult to achieve given differences in community and academic priorities [7]. Systematic reviews of CBP clinical trials and other research efforts found that few studies involved the community in the planning, implementation, analyses and dissemination of the results of the work [7, 11].

Process issues can affect how effective CBP is in meeting goals to eliminate health disparities. The extent to which funding, budgeting and governance issues, as well as roles and responsibilities as they relate to data collection, education and services are formalized, monitored and adjusted can be important to accountability and maintaining the long term efforts that are likely to affect health disparities [7]. While there have been calls to evaluate the fidelity with which CBP principles are applied [12], attempts to understand the CBP processes that lead to achieving project goals is more recent [13].

This paper describes the process of developing relationships and governance structures to guide a program focused on the reduction of cancer disparities, using CBP theoretical principles. A description of how shifts in preventive screening policy and changes in community organizations and activism affect the ebb and flow of education and screening activities is provided. The factors that contributed to the development of an evaluation process consistent with the evolving science of CBP practice is discussed in relationship to efforts to structure community input and support maintenance of relationships.

Program Overview

In 2003, SEER data indicated that all site cancer mortality in Missouri (per 100,000) was higher among African Americans (261.7) compared to Whites (198.5) and other minorities (157.2) [14]. This excess cancer burden was particularly acute in the St. Louis metropolitan statistical area and was the impetus for the development of the Program for the Elimination of Cancer Disparities (PECaD) at the Alvin J. Siteman Cancer Center (SCC), St Louis, MO of Washington University School of Medicine (WUSM) and Barnes-Jewish Hospital (BJH). PECaD was established in 2003 as an attempt to develop a national model for eliminating cancer disparities through application of the philosophy and principles of community-based participatory research (CBPR). In 2005, PECaD became one of the Community Networks Program (CNP) National and Regional Centers for Reducing Cancer Health Disparities, funded by the National Cancer Institute's (NCI) Center to Reduce Cancer Health Disparities (CRCHD) (5 U01 CA 114594). While prostate, CRC and lung cancer mortality have decreased, PECaD continues its efforts.

Governance

The Disparities Elimination Advisory Committee (DEAC), a community-based advisory group, was established at PECaD's inception. DEAC is made up of cancer survivors and advocates, representatives from health care and social service organizations, academic researchers, minority media, clinicians and staff. These relationships among the members and the Program are formalized through MOUs [7]. The original members of DEAC were

invited by the Program PIs, but new members are now nominated and elected by current members. The election procedures include a nomination process, with review of resumes and nomination statements for evidence of community participation and consideration of diversity in representation. DEAC meets quarterly, provides guidance and direction for PECaD programs, reviews the development, implementation and evaluation of cancer control and prevention activities; recommends collaborations and shares information on programs and resources.

The Leadership Team works in conjunction with DEAC and is responsible for guiding the implementation of PECaD programs and translating DEAC discussions into relevant programmatic plans. This team, comprised of the DEAC Chair, study PIs, Training and Community Outreach PIs, and the Project Coordinator (PC), is also responsible for publication and dissemination of research findings to the community, cancer center and grant agencies. The PC also serves as a Community Health Educator (CHE) who uses the resources of the NCI's National Outreach Network (NON) to build and sustain outreach and research dissemination of evidence-based cancer information.

Despite early formalized relationships, the leadership structure of DEAC has evolved over time. Initially, the committee was led by academic researchers who were interested in CBPR efforts as a method of achieving program goals. Once funding was secured, PIs continued leading committee activities; however, the Leadership Team began to question whether this structure was consistent with CBP principles that call for power sharing [3]. In 2010, DEAC began electing a community co-chair from among nominees submitted to the committee to serve with the academic/researcher Co-Chair. The Co-Chairs represent PECaD and community viewpoints on issues related to cancer disparities at national and regional meetings and plan the agenda for PECaD and DEAC meetings. The change in leadership strategy also made the Community Co-Chair a member of the Internal Leadership Team.

Programming

Program building began with several activities that permitted identification of community concerns within PECaD's capacity to respond (See Table 1). One of the first issues identified was the way research was conducted in the African American community. These concerns led DEAC to request that WUSM researchers engage in a dialogue with community members, particularly the African American community, in order to improve the conduct, relevance and influence of research on cancer disparities. To facilitate this activity, a project team conducted key informant interviews with community leaders, including minority physicians, and focus groups [15]. While members of the community recognized the importance of research, participants questioned the motives of researchers and cited inexperience as problems in the research enterprise. Participants highlighted researchers' failure to provide descriptions of projects that were easy to understand and poor dissemination of research results back to the community as barriers to participation. The minority physicians interviewed supported these issues while raising additional concerns. Minority physicians noted the failure to collaborate with community practitioners, failure to hire research/intervention staff from the community and compensation levels that failed to

address transportation, medications and the time required for participation. These results contributed to PECaD's early focus on researcher training.

The second programmatic effort formalized strategic disease partnerships and provided oversight to disparity activities, services and research for each disease. Each of four partnerships (breast, colon, lung, and prostate) is briefly described.

- The Breast Cancer Partnership (BCaP) is the oldest of the disease partnerships and is made up of cancer survivors, advocates, representatives and providers from health care and social services, academic researchers, clinicians and staff. The partnership, which began meeting on a monthly basis in January of 2006, helps to facilitate dialogue and strategic planning to address breast cancer disparities. BCaP's early efforts included education and support for survivors and currently focus on structural barriers to preventive screenings. The partnership now meets quarterly and updates its goals each year.
- The Prostate Cancer Community Partnership (PCCP), which has a similar composition as the BCaP, was originally focused on educating high-risk, African-American men about prostate cancer. Although there were earlier prostate cancer awareness activities in the St. Louis area, PECaD provided leadership. The group began meeting monthly in January of 2007 and worked with the Internal Leadership Team to secure funding for joint education and screening events with both faith based and survivor focused groups. PCCP trained men to deliver prostate cancer education and played a significant role in an early PECaD pilot grant supplement used to develop the prototype for prostate cancer education used by the group's speakers bureau.
- The Colorectal Cancer Community Partnership (CCCP) is the smallest of the disease specific groups. The Partnership's goals and objectives include education and the reduction of economic and resource barriers to screening in underserved communities. Over time the CCCP influence and membership have grown leading to input into the Full Research Trial of the most recent PECaD grant and was instrumental in developing a NCI funded grant to conduct community engaged research on CRC screening using Photovoice. The resulting Photovoice 'posters' have been integrated into PECaD Outreach activities.
- The Lung Cancer Community Partnership (LCCP), which is no longer in existence, began its activities in 2006. Members decided to focus on heightening awareness of lung cancer disparities within the medical community and the inclusion of minorities in lung cancer clinical trials. In 2008 the LCCP participated in a DEAC led conference series focused on cancer disparities to increase awareness among members of the medical community. The group also focused on youth tobacco education programs and participated actively in the Smoke Free Saint Louis Tobacco Coalition.

The third major DEAC initiative was the organization, development and implementation of recommendations from a series of Strategic Action Workshops. These agenda setting workshops were a strategy for gaining broader community input than DEAC or the disease

groups could provide. The Strategic Action Workshops were held between October of 2006 (colorectal) and July of 2007 (Lung). While broad community representation at the Workshops varied by disease group, all of the workshops were attended by researchers and representatives from health organizations. The Prostate Strategic Action Workshop included members of an American Cancer Society prostate cancer group that was ending, a faith-based cancer coalition and members of a community prostate cancer advocacy group. The breast cancer workshop included representatives of the Breast Cancer Community Partnership (BCaP) that had started to meet, the Witness Project of Greater St. Louis, the American Cancer Society and the Breast and Cervical Cancer Control Project. The lung cancer workshop included advocates from the smoke free coalitions. Workshops consisted of research presentations and interactive brainstorming, categorization and prioritization activities. A written summary, outlining future goals and objectives for each group, was distributed to DEAC and the relevant Partnership. While useful in guiding early work, this community input strategy was not sustained.

Successes

Table 1 provides a time line of Program activities. The successes of PECaD's health disparity work are strongly related to its ability to respond to partner identified concerns [9]. Breast cancer disparities activities including a partnership with a local Federally Qualified Health Center (FQHC) and support of navigator service improvement are examples. Collaboration to expand mammography service into a FQHC identified unserved region led to a grant application. PECaD identified barriers to service and strategies for implementing needed resources; funding provided a mammographer, navigation, co-pay and information technology assistance and evaluation. Evaluation data were shared with the partner and used to identify funding to incorporate mammography services into the regular service line. Similarly, a Navigator Work Group identified the need to discuss challenges to guiding women to services and ways to work around those challenges. The group, with some PECaD support, engages navigators from both Illinois and Missouri in discussion quarterly.

Education efforts have capitalized on novel partnerships [9]. PECaD brought together the Becker Medical Library and the Saint Louis Public Library (SLPL). This partnership, established in 2008, uses the library as a central "hub" for the community to receive health information. PECaD has cancer resources in informational kiosks at five SLPL libraries located in areas with high mortality rates and two *Eight Ways to Prevent Cancer* [16] DVDs are circulating through all 19 of the SLPL library branches. PECaD also provides training on identifying reputable health resources to SLPL staff so that they are better able to assist community members seeking health information. The library effort expanded to include the integration of cancer prevention information and resources into existing kiosks in the County Library system, resulting in PECaD's ability to reach more than 200,000 residents throughout the Saint Louis Metropolitan Area and a bill board campaign (making 12,911,000 impressions) to efforts.

In addition to standard community disparities education, PECaD researchers have developed and implemented a community education model to facilitate co-learning [10] between academic and community partners wishing to engage in community based participatory

research (CBPR) [17, 18, 19]. Implemented in 2013, the Community Research Fellows Training was adapted from the CARES training [20] and enhances community potential to engage as equals with academic researchers [10, 19]. It has trained 83 community members, with participants now engaging in diverse activities that include Partnership participation, research project coordination and advisory board service.

Challenges

The disease partnerships are the components of the PECaD CBP effort that appear to have experienced the greatest challenges as the program transitioned through shifts in cancer screening policy and funding cycles. Further, community organizations grew and matured, which resulted in changing interests and desires to partner. Despite its original focus, disparity awareness among physicians and medical researchers was never a priority activity. LCCP activities targeted development of local smoke free coalitions and environment legislation almost exclusively. With policy advocacy successes and the strength and viability of community tobacco free coalitions and organizations to continue youth education activities, activities waned and LCCP dissolved by the end of the initial CNP funding cycle.

The CCCP's issues were different; CRC screening access was a major CCCP focus in underserved communities. The CDC funded Missouri Screen for Life program lost funding that was not replaced at similar levels and challenged the CCCP's strategy for addressing CRC screening barriers. In 2008, with new research leadership, a reinvigoration effort was initiated that brought new survivors and family members to the group. Using supplemental funds, a nominal group process was used to assist members to identify and select activities that include community education events and the development of a CRC resource guide. The group now plans to review its goals every 2 to 4 years.

From 2007 to 2010, PECaD facilitated training of community members who participated in a Speakers Bureau that provided prostate cancer education and screening information. Over this time, research partnerships outside of PECaD expanded and prostate partners began to provide screening events and survivor support activities beyond those that were offered through PECaD. Changes occurred in prostate cancer screening recommendations and policy that affected funding to support PCCP screening efforts [21]. The shift in PECaD's ability to support screening activities was related to funding changes that followed the policy shift [21]. Given this shift and the depth and breadth of partner activities, PCCP recognized the need to determine new goals and priorities and became a support for partner organizations.

Issues of accountability have emerged as a major challenge [7]. Although active and stable, BCaP continues to express a desire for more frequent data sharing [9]. PCCP members verbalized their frustration with what was perceived as a lack of input and leadership from academic research partners in response to changes in prostate screening guidelines. Neither group felt that the DEAC response to input was sufficient. The DEAC itself, with input from the Internal Leadership Team, recognized that while there had been informal assessments and discussions there were no formal methods for evaluating partnership effectiveness, whether in terms of implementation of CBPR principles and community relationships or

program goals and objective. In 2011, a formal evaluation was implemented that highlighted gaps in community representation on the DEAC (see Table 2 for overview of evaluation).

Discussion

PECaD has come to appreciate the opportunities and challenges that adherence to CBP principles generates. Using a layered leadership strategy and with three of four disease partnerships continuing, PECaD has successfully engaged community partnerships to inform health disparities research and outreach. It has avoided the loss of program activities [9] and has a framework for moving forward. While useful, maintaining disease rather than research focused partnerships has presented challenges. Clearly there is no “one” way for Partnerships to function; each Partnership is comprised of different stakeholders, so the groups set levels and inputs with which they are comfortable. While some partners have expressed frustration with researchers’ level of input, other partners have advocated for greater community input and this ongoing tension must always be addressed.

Implementation of strategic planning and ongoing evaluation of the partnership has resulted in adjustments of DEAC/Leadership Team representation and processes. Systematic evaluation and periodic review are now used to ensure appropriate and meaningful activities that allow partners and researchers to collaboratively respond to changing policy and funding environments in mutually satisfying ways [7]. In addition, they are used to identify priorities, gaps in research, education and services that support collaborations that will eliminate cancer disparities. Our experiences and evolving evaluation activities have led to the following lessons.

1. Advisory board and partnership discussions are insufficient to identify and assure resolution of conflicts and concerns between and among partners. Formal processes are essential to adequate response and we are now developing these.
2. Evaluation data must be systematically reviewed with the community to assure that representation and input are sufficiently diverse. Our last review led to a targeted membership expansion.
3. Our failure to evaluate CBP principles early in our work contributed to the failure to observe principles and to hear and respond to emerging concerns among partners. For example, shared leadership was not recognized as an issue until 2010. Interestingly, the area of concern not assessed in our current evaluation - recognition of conflicts, constructive conflict resolution and agreed upon problem-solving processes- are the areas that have generated ongoing concerns among partners and must be addressed.

Acknowledgements

We gratefully acknowledge the community members and partners who participate in Program for the Elimination of Cancer Disparities activities and planning. We thank our academic partners and staff for their valuable contributions. Primary support for this program is through the Community Networks Program Center grant U54 CA153460 (PI: Colditz). We gratefully acknowledge supplemental funding through Siteman Cancer Center and the Foundation for Barnes-Jewish Hospital.

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Table 1

Highlights of PECaD Activities and Achievements

| | |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------|
| 2003 | |
| DEAC established | Ongoing |
| An institutional strategy to increase minority recruitment to therapeutic trials. There has been approximately a 3.1% increase in minority accrual to clinical studies since 2005. | Publication 2013 |
| 2005 | |
| NCI Community Networks Partnership Funding | Refunded 2010 |
| 2006 -2007 | |
| Identification of community concerns and priorities through strategic action workshops | Last updated 2013 |
| Supported research to describe the network of cancer support service providers in the metropolitan area for minority & underserved patients and examine how network agencies interact and collaborate with each other. | |
| Disease partnerships established (LCCP disbanded) | Ongoing |
| Pilot funding to develop a tool to facilitate informed decision making in prostate cancer community outreach to African American men | 2007-2008 |
| Prostate cancer education | Ongoing |
| Research on breast cancer presentation in an urban health care safety net system | Publication 2011 |
| Collaboration to identify patient and process factors contributing to late stage breast cancer presentation | Publication 2012 |
| Lung cancer disparities awareness training | |
| Smoke free coalitions and campaigns | 2007-2008 |
| Youth anti-smoking and cancer education | 2007-2008 |
| 2008 | |
| Pilot funding to explore African American parents' knowledge of HPV & HPV vaccination | Publications in 2011, 2011 |
| Minority supplement to study use of technology to provide colorectal cancer education to African American men | Publication in 2013 |
| Education and prevention messages in the African American newspaper | 2008-2013 |
| 2009 | |
| Patient navigation for breast cancer screening (of the women navigated, 94.5% got a mammogram during the study period) | 2009-2011 |
| Reporting research findings back to the community | Ongoing |
| 2010 | |
| PECaD Newsletter to over 400 academic and community partners | Ongoing |
| Quality improvement breast cancer regional navigation work group formed | Ongoing |
| Established formal training program (14 research professionals trained) | Ongoing |
| Pilot funding to assess barriers to minority participation in tissue research | Completed 2012 |
| Public Library community cancer education capacity building | Ongoing |
| Faith-based community cancer education capacity building | Ongoing |
| Colorectal cancer screening randomized control trial | 2010-2015 |
| 2011 | |
| Education and prevention messages on the radio (24 live interviews) | 2011-2014 |
| Photo Voice project to engage community members about colorectal cancer screening | 2011-2013 |
| 2012 | |

| | |
|---------------------------------------------------------------------------------|------------|
| Education and prevention messages with St. Louis metro transit | |
| Pilot funding for Community Research Fellows Training (CRFT) | 2012-2013 |
| CBPR approach to improving breast cancer services for women living in St. Louis | 2012-2014 |
| 2013 | |
| Supplement to expand CRC Outreach/Partnership | 2013 -2014 |
| Library outreach expanded | |
| 2014 | |
| Colorectal cancer community education workshop | |
| Institutional funding for Community Research Fellows Training (CRFT 2) | 2014 |

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Table 2

Progression of PECaD CBP Evaluation

| | 2003 -2007 | 2007 - 2010 | 2011-2014 |
|----------------------------------------------------------------------------|------------|-------------|-----------|
| Scientific Progression | | | |
| Peer reviewed publications | X | X | X |
| Grants applied for | X | X | X |
| Community Engagement in PECaD | | | |
| New community-academic research partnerships developed | | X | |
| Level of engagement in each partnership (years involved, role, activities) | | X | |
| Research questions or projects emerging from existing collaborations | | X | |
| CBPR Survey* | | | X |
| Community Attitudes Toward Medical Research | | | |
| Focus Groups | X | | |
| Pre/Post Tests following community research training | | X | |
| CBPR Survey* | | | X |

| | |
|----------------------------|----------------------------------------------------------------------------------------------------------------------|
| *CBPR SURVEY TOPICS | Characteristics of the partnership (geography, organizations, gender, race/ethnicity, length of participation, role) |
| | Accomplishments of partnership |
| | Overall effectiveness on CBPR Principles (1, 2,3, 4,6, 7, 8, 9) |
| | New partnerships and research questions/projects developed or emerging from activities |
| | How well partnership uses members' time |
| | Level of influence of self and others in group in partnership |
| | Facilitation of member involvement in partnership |
| | Member satisfaction with role in partnership |
| | Membership satisfaction with influence in partnership |
| | Comfort level for expressing opinions in partnership |
| | Perceived level of openness in partnership |
| | Perceived level of trust in partnership |
| | Community benefits of participation |
| | Community empowerment |
| | Institutionalization of programs and/or partnerships |