Community Participation in Health Initiatives for Marginalized Populations

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Abstract: Community-based participatory methods have emerged as a response to conventional approaches that have historically failed to make notable improvement in health status or reduce chronic disease among marginalized populations. The social-ecological model provides a framework to develop and implement strategies directed to affecting multiple levels (societal, community, organizational, and individual) of influence on health status. A systems approach can facilitate the identification of the complex interrelationships of factors at all levels that contribute to health disparities by making use of the unique knowledge, expertise, and resources of community partners. Community engagement in the planning, implementation, and evaluation of health initiatives builds community capacity to create sustainable changes at all levels to achieve and maintain optimal health for those who bear the greatest burden of disease. Key words: CBPR, community participation, disparities, marginalized communities

Those who are economically disadvantaged and socially excluded bear the greatest burden of chronic disease and face the greatest challenges in initiating and maintaining optimal health. Systemic barriers to achieving positive health among the most vulnerable are created from inequitable distribution of resources such as transportation, economic assets, employment opportunities, healthcare, and toxin-free environments. Psychosocial factors also contribute to inequities such as community norms, membership in different cultural groups, interpersonal relationships, social status, and intrapersonal beliefs. The social-ecological model provides a framework to understand disparities and inequities at multiple levels of influence: societal, communal, organizational, and individual. For example, at a society level, interventions may be directed to changing policy relevant to how resources are allocated or used within a community or state, whereas at the individual level, interventions may be directed to changing individual knowledge, beliefs, or behaviors. Community participation at all levels can serve as an effective pathway to multilevel interventions that lead to sustainable changes that will reduce disparities and improve health status.

Community-Based Participatory Approach

Community-based participatory approaches (CBPAs) have emerged in response to multiple influences including rising chronic disease incidence and mortality rates among the disadvantaged, poor results achieved by investigator-driven intervention research, accusations by community leaders that researchers were exploiting them, and an increase in the sophistication and organization of disadvantaged communities. These approaches marry conventional methods of health promotion with community
organization, action research, and community psychology to create more efficient and lasting solutions to the problems that create health disparities. Successful community health participation initiatives rely on coalitions consisting of conventional organizations (typically not community-based) that provide services to vulnerable populations, such as clinics, social service agencies, and academic institutions, and less conventional stakeholders that include community-based organizations such as neighborhood organizations, churches, public schools, grassroots groups, in addition to businesses and other venues that serve people where they live, work, or play. Collectively, community organizations and business leaders can help develop and guide the research effort, assist in developing culturally appropriate messages, participate in implementation of interventions, and serve as "gatekeepers," to ensure the promotion of an intervention, and can help steer the health promotion efforts toward goal achievement. The heart of CBPA, unlike conventional approaches, is to involve community stakeholders as equal partners in every step of the process from identifying problems, setting goals, creating interventions, implementing strategies, and evaluating and disseminating information learned back to the community (Israel et al., 1998).

Community participation in the development and implementation of initiatives are likely to be more effective than conventional approaches alone because the assets and resources inherent in the community of interest are identified and mobilized in a culturally appropriate manner. Community knowledge of the complex interactions between economic, social, and behavioral factors that influence health status can inform the design and implementation of culturally sensitive interventions. Furthermore, the practical advice and strategies provided by the community can greatly increase effectiveness in recruitment and continued participation in health projects. In addition, by sharing power, knowledge, skills, and resources, partners build mutual respect and trust that will increase the community’s capacity to sustain changes and initiate further actions.

The CBPA is based on principles that include the following:

- recognizing the community as a unit of identity;
- building on collective strengths and shared resources;
- promoting a colearning and empowering process that attends to social inequalities;
- using a cyclical and iterative process in which community input guides quality improvement;
- facilitating partnership and capacity building throughout the process;
- disseminating pertinent information, data, and other findings to all participants;
- involving a long-term process and commitment; and
- seeking balance between research and action (Israel et al., 2003).

In 1997, the Centers for Disease Control and Prevention initiated Racial and Ethnic Approaches to Community Health (REACH) in 40 communities to eliminate health disparities in the health status of African Americans, Alaska Natives, American Indians, Asian Americans, Hispanics, and Pacific Islanders. REACH used CBPAs to reduce risk factors and the prevalence and impact of chronic diseases including breast and cervical cancer, cardiovascular disease, diabetes, and HIV/AIDS (Tucker et al., 2006). Local strategies were community-driven, multilevel (individual, family, provider, and policy), occurred in multiple settings and through community coalitions that engaged diverse community partners including the faith community, academic institutions, healthcare organizations, and grassroots groups. In North Nashville, Tennessee, the project focused on eliminating disparities in diabetes and heart disease among African Americans by targeting tobacco use, access to healthcare, health screenings, and overall health and wellness. Achievements of the initiative included increased access to healthcare by expanded hours of operations in safety net clinics (Centers for Disease Control and Prevention, 2007), a community campaign to reduce smoking (Larson et al., 2009), increased community capacity to conduct screenings (Patel et al., 2009), and improved
diabetes self-management (Greene et al., 2006).

Community participation can serve to bridge the multiple levels of influence that impact health. By bringing together the strengths and resources of stakeholders who vary in type and extent of material and social resources, social capital is increased that can facilitate empowerment to leverage change at the different levels of need.

**FRAMEWORK AND STRATEGIES**

A systems framework (Senge et al., 1994) can promote effectiveness in the development and implementation of community-based participatory approaches and strategies for health promotion and disease management. Instead of seeking to identify simple cause-and-effect relationships as the basis for interventions, a systems framework encourages viewing problems as embedded in networks of interacting forces that create and sustain social inequities and health disparities. Systems analysis allows the identification of a multiplicity of potential lines of causal influence and encourages understanding of how these influences interact as part of a larger system. Systems' thinking encourages multi-level and multidimensional interventions as opposed to seeking a single intervention to solve a problem. The systems framework is ideal for community-based participatory approaches because all partners are a part of the system and can be thought of as engaged components within the system. Each partner determines how its particular strengths and assets can be used to impact the causal or contributing pathways and problems. Resources, processes, and strategies can be aligned and leveraged in more systematic ways to achieve desired outcomes.

For example, organizational and business leaders who are vested in the community of interest can serve as powerful spokespersons and communicators to deliver strategies and messages to facilitate policy changes. Community members who are peers within the network of the population of interest can serve as educators and navigators by delivering culturally sensitive strategies and messages to facilitate individuals' health behavior changes. Community and economic development may have more profound and lasting impacts on population health than traditional health education approaches.

The CBPA is also ideally suited for the application of quality-improvement tools and methods. This approach allows for smaller-scale evaluation as compared with traditional models of pre-post assessments or randomized trials so that as outcomes are monitored continuously over time, the interventions can be modified on the basis of continuous learning about its effectiveness. Building in an iterative process is a key component of CBPAs that differentiates it from traditional community-based approaches.

**MULTISTAKEHOLDER PARTNERSHIPS**

Diverse community participants including the faith community, neighborhood organizations, community clinics, business and retail establishments, academic centers, public schools, and others are critical to identifying the health issues on which to focus and to ensure that a shared vision is created and monitored. It is essential that community partnerships include specific expertise to assist and guide the identification of the health problems or issues. This may include academic, government, or healthcare agencies whose representatives have access to data and tools that can be used to inform community partners about the nature and scope of the health issues. Presence of this expertise in the partnership can ensure that monitoring the outcomes of the initiatives will occur in a manner that ensures accuracy and timeliness of findings. Community leaders as partners who represent organizations and businesses can support their community constituents by encouraging involvement and offering support to do so. They can provide resources of time, material support, and even small financial support, as well as participate in strategy development. However, it is of the highest importance that those community members who are directly impacted by health, social, or environmental problems are well represented in the problem identification phase.
Community participation at the organizational level also enables the use of distributed and shared resources when external funding through grants or philanthropic procurement is scarce. Many communities have attained success by developing large, diverse, and multidisciplinary partnerships that resulted in increased capacity to implement and evaluate health initiatives at macro and micro levels that address needs in specific geographic areas. For example, a large coalition-driven community-based participatory seat belt use initiative in collaboration with the National Conference of Black Mayors, in Jackson, Mississippi, revealed that over a 5-year period, multiple and multilevel community education, messaging, and public policy campaigns resulted in passage of primary seat belt legislation (allowing law enforcement officers to stop and cite motorists solely for lack of seat belt use). This successful community initiative led to increased belt use among African Americans and a marked decrease in motor vehicle crash-related morbidity and mortality statewide. Strong local partnerships between the healthcare community, academic institutions, the faith community, government, and the business community with support from researchers from Meharry Medical College were instrumental in ensuring success (Goldzweig et al., 2008). Community leaders can be instrumental in bridging concerns, ideas, and strategies of community residents with portals to make systemic changes that impact social determinants and health inequities.

Participation at the community resident/member level brings a wealth of culturally sensitive knowledge to inform interventions including cultural beliefs or practices, appropriate language level, social norms, health literacy, as well as challenges that occur in their daily lives. These factors among others should be considered in the development and implementation of strategies to increase the likelihood of achieving success in improving health status. Collectively, the participation of community members contributes to building the capacity of the community as a whole. Applying a train-the-trainer model for peers to become leaders and educators for behavior change builds resources within the community and is effective for improving health status. For example, peer educators and peer role models have been successful in modifying the health behaviors of low-income prenatal teens to ensure positive birth outcomes (Ford et al., 2001). Peers as healthcare navigators have been successful in linking HIV-positive individuals with medical treatment and resources and improve continued adherence to care (Bradford et al., 2007; Malone & Osborne, 2000). Peer-to-peer education in high schools, using a service-learning model of interactive education with students as leaders, has shown success in increasing teen seat belt use in urban high school settings (Bradley et al., 2007). Peers are more likely to be effective because of cultural sensitivity, mutual trust, and respect among community members within the population group of interest. Populations have been marginalized in part because of lack of respect, recognition, and abuse of trust from the population who holds the wealth and power.

**THE PROCESS OF ENGAGING COMMUNITIES**

Engaging communities in solving health problems can be divided into 3 partially overlapping stages as depicted in Figure 1: (1) planning, (2) implementation, and (3) evaluation. The double arrows between the stages indicate that the stages overlap and interact. Within the planning stage, work begins at the bottom of the diagram and moves toward the top. Double arrows indicate that these steps are not always distinct or linear and that planning is an iterative process that involves a series of functions that are sometimes repeated until a viable plan emerges. Community engagement refers to identifying, making contact with, and involving the community in planning and preparation activities. This step may also involve the development and fostering of coalitions of groups that represent the community, serve the community, and/or wish to engage in community research. Capacity building and community
organization occurs when researchers and other coalition members take steps to enhance the ability or capacity of a community, community organization, and other partners to take action to improve health or to make other important changes or decisions. Needs assessment involves the collection of data on the community, its needs, and its assets using qualitative and quantitative methodologies. Goals and objectives are chosen on the basis of community needs and preferences, and a research plan is developed, including a plan for evaluation. Throughout this process, researchers and community representatives are working on the development of a logic model that describes the context, needs, goals, plans, and intended outcomes of the project.

Implementation of a project involving the community begins with administrative preparations in which sites are selected, a memorandum of understanding is written and signed (when appropriate), and personnel are hired. Some collaborations remain informal, while others need to be formalized with a contract or a memorandum of understanding. The research begins by mobilizing the community and implementing the planned actions. A process evaluation, in which data are collected to document the actions taken to implement a project and fidelity of interventions to the plan, is an important aspect of the implementation phase. Some projects may require a data safety and monitoring plan as part of research implementation.

Evaluation involves selecting tools and strategies to collect data on short-term, intermediate, and long-term outcomes, including impact on public policy and population health. A method must be developed to collect, monitor, enter, and manage data, including plans for quality assurance (Schlundt et al., 2001). Data analysis occurs throughout a study, beginning with an examination of preintervention data and continuing until the end of follow-up. Dissemination involves the reporting of results and findings in professional journals and meetings, reports to local community media, local presentations, and also includes communication of study findings back to the participating community coalition. Finally, once programmatic activity has been completed, an opportunity exists to evaluate the extent to which the work has

Figure 1. The community-based participatory approach process.
resulted in sustained activity or improved outcomes in the community.

A CIRCUMPLEX MODEL OF COMMUNITY ENGAGEMENT

Engagement of the community in health projects, interventions, and programs can be conceptualized in a Circumplex Model of Community Engagement (CMCE). This model (Fig 2) displays the participation level of the community on the horizontal axis with the participation level of conventional entities such as academic institutions, health clinics, and state and local health departments on the vertical axis. The CMCE provides a framework for understanding and plotting the level of community engagement and using this information, if needed, to devise ways to improve community input by utilizing community-based participatory strategies like focus groups and community advisory boards.

The upper right quadrant in the CMCE displays the goal of equitable participation of community and noncommunity stakeholders. The other quadrants show imbalance in the partnerships that are likely to lead to less than successful outcomes. Historically, we have operated in the upper left quadrant where investigator-driven methods have been used with little to no community input or participation. This method has not made notable improvements in the health status of marginalized communities. The lower right quadrant displays an imbalance where community participation is high and conventional input is low. This approach often loses the systemic visioning that can occur with diverse partnerships and the monitoring of outcomes that is critical to ensuring that outcomes are achieved. The lower left quadrant is essentially the absence of interventions, which is too often the status quo in communities. This model in concert with continuous quality improvement monitoring can assist in ensuring that equity in power and decision making are maintained throughout the process of health initiatives. Maintaining

Figure 2. Circumplex Model of Community Engagement.
equity in community collaborations may build greater trust and respect among all parties that have the potential to reap great social and health benefits. The health challenges facing our nation require strong, dedicated collaborative work between all partners to develop, implement, and evaluate culturally competent strategies at the community level if we are to successfully address and overcome them by informing policy and inspiring structural changes in healthcare systems and in communities.

REFERENCES


