Is Community-Based Participatory Research Possible?

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Abstract
The researcher seeking guidance in conducting research that is truly community-participatory may find too much guidance rather than too little and must recognize that his or her project will be evaluated not only on the quality of the science, but on the extent to which it adheres to the principles of CBPR.

Community-based participatory research (CBPR) is a relatively new research model in which the research process itself is intended to benefit research participants and the communities in which they live. It is often represented in the “Community Engagement” core of NIH-funded Clinical and Translational Science Awards (CTSA) and is usually part of the research portfolios of CDC-funded Prevention Research Centers. Apart from the CTSA initiative, NIH has recently published requests for applications that explicitly call for CBPR proposals.1,2 Promoted by these and other funding opportunities, the use of the CBPR approach has grown. Yet, as will be explained shortly, CBPR practitioners face a number of unique challenges that threaten the CBPR model. To each of these challenges, however, there are potential responses.

Research has long been conducted in communities: a PubMed search on the term “community-based research” lists nearly 16,000 publications since 1971. On the other hand, a similar search on the term “community-based participatory research” lists fewer than 1000 publications, with the first citation in 1980. However, the number of CBPR publications has increased each year, from 4 in 2000 and 34 in 2001 to 541 through the first 10 months of 2010.

The difference in the two types of research lies in the role of the community. The term “community-based research” merely signifies that research took place in the community, as opposed to the laboratory, clinic, or hospital. In CBPR, however, the research team or institution enters into a partnership with the community, and the community is to play an equitable role in every phase of the research: identifying the research topic and the research question, planning and executing the project, collecting and analyzing the data, and disseminating the results.3–5 Hence, CBPR is not a research method or a study design but is rather an approach that is intended to give the community authority in the research project—a form of community empowerment. A generally accepted definition was offered in a review commissioned by the Agency for Healthcare Research and Quality (AHRQ):4

Community-based participatory research is a collaborative research approach that is designed to ensure and establish structures for participation by communities

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affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change.

Principles and standards for the CBPR model have been articulated frequently. An oft-cited review by Israel and colleagues\textsuperscript{3} lists nine principles that can be used to evaluate the extent to which a community authentically participates in research (although the paper does not actually use the term \textit{participatory}). Green et al. developed a 23-item checklist by which CBPR grant applications could be reviewed and rated.\textsuperscript{6} The review commissioned by AHRQ proposed a set of 11 “critical elements”\textsuperscript{4} The organization Community–Campus Partnership for Health, which promotes CBPR, has formulated ten “Principles of Good Community–Campus Partnerships.”\textsuperscript{7} The NIH Council of Public Representatives developed 13 values for community-engaged research and 12 criteria for grant applications for research involving communities.\textsuperscript{8}

Of course, many of the principles in the various sets are fairly general and express similar ideas. For instance, “Facilitates collaborative partnerships in all phases of the research”\textsuperscript{3} is similar to “Does the research process apply the knowledge of community participants in the phases of planning, implementation and evaluation?”\textsuperscript{6} and “The community partner is involved in all aspects of the research, from planning through dissemination of results.”\textsuperscript{8} On the other hand, some principles are specific and not widely reflected, such as “The application includes a plan to train community partners in research methodology.”\textsuperscript{8}

Hence, the researcher seeking guidance in conducting research that is truly community-participatory may find too much guidance rather than too little and must recognize that his or her project will be evaluated on not only the quality of the science, but also the extent to which it adheres to the principles of CBPR.

The Pillars of Community-Based Participatory Research

Notwithstanding the plethora of principles, CBPR rests on two main pillars. The first is ethical and responds to a history of exploitation of communities—especially minority and low-income communities—in the name of research. The most notorious U.S. example is the Tuskegee Syphilis Study,\textsuperscript{9} but the residents of many communities can recall university researchers who came to conduct interviews or take samples and then vanished.\textsuperscript{5} The academics presumably published, won grants, and were promoted, while the research subjects and their communities received no benefit.

The second pillar—community empowerment—has roots that are often attributed to the writings of the Brazilian educator Paulo Freire.\textsuperscript{10} Its domestic pedigree lies in the principle of “maximum feasible community participation” that guided the poverty programs of the late 1960s and early 1970s.\textsuperscript{11} Initiatives such as Headstart and community health centers had, and still have, community-majority governing bodies. This represented recognition of the fact that low-income communities rarely have any control over the programs that have an impact on their lives, such as schools, medical facilities, and public housing. If these communities can gain a modicum of power over these important aspects of their lives, the argument goes, they will be better-positioned to address the social determinants of health\textsuperscript{12} and break the “cycle of poverty”: poverty begets powerlessness, which in turn begets poverty. This pillar incorporates those activities that lead to community empowerment, such as social action and sharing of resources.

A number of similar approaches have been described, both in public health and social sciences research. These include “participatory action research,”\textsuperscript{13} “action research,”\textsuperscript{14} “participatory research,”\textsuperscript{15} “community-partnered participatory research,”\textsuperscript{16} and a number of
others. Although these vary somewhat in their approaches, they all ultimately rest on these two pillars—although the term pillars is not used elsewhere in the literature on CBPR or its variants.

Practically, there are several approaches to partnering with the community that are consistent with these two pillars. In most cases, the community is represented by a Community Advisory Board or CAB\textsuperscript{17} (sometimes known as a Community Research Advisory Board, a Community Coalition Board, or similar). There may be a single board for a research center that houses multiple projects, or there may be a board for a single project. Alternatively, an academic institution may partner with a community group that was organized for a different purpose—for instance, an advocacy organization, a church, or a neighborhood association. Community input regarding leading health problems and local assets may be obtained through surveys or focus groups, but sustainable community participation in the planning and execution of a research project, or a research program, requires the presence of a permanent group of citizens.

The Challenges

Adherence to the complete CBPR model—equitable community participation in every phase of the research project—presents a number of serious challenges. The first is defining the community. It may be difficult to recruit a sufficient number of participants for a research project from a small geographically defined community. On the other hand, a large community that is not defined by geography (for instance, “the African-American community”) may be too diffuse to enter into a meaningful partnership. A suitable compromise may be reached by developing a partnership with a well-defined but relatively small community, recruiting research participants from that community to the extent possible, and then doing additional recruitment in similar communities as needed.

A second challenge is identifying CAB members who truly represent the community and are therefore qualified to give ethical consent to research on the community’s behalf. Communities are not monoliths and may not be well represented by volunteers, by agency workers (who generally do not live in the community served by the agency), or even by local elected officials, who are often viewed with suspicion as the representatives of special interests rather than the voice of the grassroots. Again, the best solution may be compromise: some combination of people in these categories, always including community “gatekeepers” or leaders.\textsuperscript{18}

A third challenge is that of generating a genuine commitment to research on the part of communities and their residents. Especially in low-income communities, residents are usually interested in services, resources, and jobs, not in being studied. Bridges can be built by providing services either as part of or as ancillary to a research project and by hiring community members as research assistants, but the risk of co-optation is great.\textsuperscript{19}

In CBPR, the community is to be offered the opportunity to choose the health problem to be studied, but this may be determined instead by the particular expertise of the partnering researchers or the priorities of funders. This may be addressed by the researchers in the context of a strong and trusting community partnership by making a good-faith effort to recruit and engage colleagues with expertise in the community priority area. The community is also to be offered the opportunity to participate in the analysis and interpretation of results, but this is often limited by the need to perform complex analyses that are the province of biostatisticians and other scientists. Although community members cannot usually contribute to statistical analyses, they can contribute to an understanding of the social and cultural factors underlying the results.\textsuperscript{16}
For their part, academicians often complain that IRBs do not understand CBPR and therefore may impose onerous requirements (for instance, detailed consent documents for seemingly minimal-risk projects) or needless delays. In fact, the mission of IRBs is to protect individual research participants rather than communities, hence, the training of IRB members and the regulations under which IRBs operate may not be appropriate in some respects for reviewing CBPR protocols. A second common academic issue is the contention that CBPR is more time-consuming than traditional research approaches; the partnership-building process itself may take months or years.

In addition, agency staff may have to be recruited and trained as researchers, community priorities and community leadership may change, and other unforeseen obstacles may arise. Hence, the typical timetable for promotion and tenure may discriminate against faculty who pursue this type of research. Although there are a number of CBPR faculty at various institutions who have published and gained promotion, addressing this issue more comprehensively may require amending promotion policies.

Any particular CBPR study risks criticism both from the cadre of CBPR practitioners and from more-traditional research scientists. From the former may emerge the allegation that the project is not sufficiently community-participatory—that the community was not adequately represented, for instance, in the design or implementation of the project. From the latter may come the charge that the research itself is insufficiently rigorous, that the interests of the community have superceded the rigor of the research, and that the project is actually “community outreach” rather than real research. In fact, the AHRQ review cited earlier concluded that “many CBPR studies had strong community–institution collaborations; relatively few combined this type of collaboration with solid research methods.”

Conclusion

Gaining a perfect or near-perfect score on the various sets of principles and criteria may be, if not impossible, certainly difficult. However, they represent targets or goals to pursue and their pursuit has had a salubrious effect on the way in which research is conducted in communities and on the research initiatives that are undertaken. With regard to the two pillars on which the CBPR approach rests, there are few hard data on the extent to which CBPR has led to community empowerment or reductions in poverty, but there are many anecdotal and case reports that suggest that the process of CBPR does, indeed, benefit communities.

Moreover, CBPR has helped turn academic researchers toward exploring approaches to addressing the social determinants of health. And although the old abuses have not disappeared, there is reason to believe that research in communities is now more ethical than in years past: Communities are less vulnerable to exploitation, and academicians are less likely to pursue exploitative research. In the real world, pristine CBPR may be achieved rarely, if ever, but its pursuit is worth the effort.

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