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REFLECTION

On Some Practical Considerations Regarding Community-Based Participatory Research for Addressing Cancer Health Disparities

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Abstract There is a consensus about the benefits of community-based participatory research and the important role it can play in reducing cancer health disparities. Although every community-based participatory research project is unique in many ways, several fundamental issues deserve consideration. We discuss issues concerning community representation, possible tensions within community-based participatory research (CBPR) projects, and staffing CBPR projects. Flexibility, open-mindedness, transparency, and above all, caring, are characteristics that best ensure successful and rewarding outcomes.

Keywords Community · Community-based participatory research · Cancer · Health disparities · Research · Rural

Introduction

The disproportionate burden of cancer among African-Americans is well-documented in periodicals and federally sponsored reports such as the Institute of Medicine's (IOM) *Unequal Burden of Cancer*: *An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved* [1]. Historically, African-Americans have had higher incidence, higher mortality, and poorer survival for many types of cancers than whites [2]. Cancer is expected to surpass heart disease as the leading cause of death in the USA within the next 20 years. When this epidemiologic transition occurs, cancer prevention and control efforts that focus on African-Americans will be needed more than ever. Data provided by Smith et al. [3] suggest that there will be a 64 % increase in cancer incidence among non-Hispanic blacks by the year 2030. The leading cancer sites are not projected to change. Cancers of the prostate, lung, and colon/rectum are expected to remain the leading sites for men, while cancers of the breast, lung, and colon/rectum will continue to be the most common sites among women [3]. Given the challenges that lie ahead, culturally relevant cancer prevention and control approaches will be needed for African-Americans.

There is a consensus about the benefits of community-based participatory research (CBPR) and the important role it can play in reducing cancer health disparities for populations by combining culturally relevant knowledge and action for social change and social justice [4–6]. CBPR has proven to be especially valuable with respect to the recruitment and retention of individuals from minority and medically underserved communities where mistrust concerning medical research is relatively high [7–9]. Indeed, because of that, CBPR has grown exponentially since it was first used as an approach for dealing with health issues in African-American communities in the early 1990s [10]. CBPR has been used as a cancer prevention and control strategy for African-American communities with a number of different disease sites (e.g., breast, colorectal, prostate) across the continuum of care in both urban and rural settings [4, 7, 9, 11]. It is now the primary approach of the 23 community network program centers (CNPC) that were funded by NCI's center to reduce cancer health disparities (CRCHD) to

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work with minority and underserved communities around the country on cancer research [12].

The principles of CBPR are laid out in more detail elsewhere [13, 14]; in short, CBPR relies on a fairly extensive collaboration between researchers and community members (individuals, organizations, agencies, etc.) where the research is being conducted. It involves collaboration from the onset, continuing throughout the project, and extending through the dissemination of the findings. Arguably, it is more of an orientation to research than a particular method because there is an attitudinal aspect in that the researcher and community have to genuinely believe in it and often both qualitative and quantitative methodologies are employed [13, 14]. Implementing the spirit and ideals of CBPR in cancer prevention and control research can be challenging because practical considerations often must take precedence over ideological notions. This essay revolves around three themes: community representation, possible tensions within CBPR projects, and staffing CBPR projects. It concludes with advice that may be useful to researchers interested in improving lives and reducing cancer disparities using a CBPR approach.

Community Representation

Two fundamental assumptions of CBPR are that (1) there is a somewhat defined community that (2) contains a collection or group of community members who truly represent the community's views. But how does one determine who best reflects and represents the "community?" This is a critical issue and one where the ideal and spirit of CBPR may not reflect the reality as it is often practiced.

There is often an established or existing power structure in a community upon which researchers rely. Time considerations associated with grants, where results are often expected within 1–5 years, may drive some of these relationships for the sake of expedience, along with ease and convenience. For instance, existing leaders and agencies and community groups such as a church or a civic organization may have an infrastructure or connections in place to help facilitate cancer education or screening projects. But is a pastor or neighborhood organization leader always a community leader in the sense of having or reflecting the pulse of the community? And are all community members equal? Might a congregation member who is a cancer survivor be better prepared to be the community lead on a cancer education and screening initiative? These are critical questions that should be answered, and early on, because CBPR strives to be representative.

Identifying community representatives based primarily on the existing power structure or establishment may simply promote or ensure the maintenance of the status quo. On the other hand, these types of "insiders" may be requisites for change or reform. It is possible that a well-intentioned researcher may end up promoting, legitimizing, or reinforcing the socially visible community members at the expense of the typical community member or those most in need of help. One promising approach to finding the less socially visible participants is to tap into local contexts in which everyday citizens can be found, such as barber shops, beauty salons, and churches [7]. However, when conducting CBPR among church communities, it is important to remember that churches often have power structures that should not be allowed to dominate investigative activities. Researchers may be able to abdicate responsibility or accountability for outcomes to varying degrees by claiming to take a greater hands-off approach, but CBPR is about helping and improving communities and involves collaboration, not benign neglect.

A related issue concerns whether only the actual members of particular communities can represent those communities. Green and Mercer [15] argue that people outside of the community of interest may play important leadership roles within those communities as well, on projects that are geographically defined or based on disease characteristics. The literature on this issue consistently suggests that "cancer outsiders" such as physicians, community health advisors, religious leaders, and others who have not been diagnosed play meaningful roles and provide important input on cancer program development and recruitment and retention strategies.

Cancer educators seeking to develop a CBPR project must also keep in mind that communities are dynamic, with people moving in and out. Consequently, knowledge and power can reside in many places. For instance, a respected pastor in a nearby community, the head of the Department of Health in another community or county, or a major employer may be quite influential in communities outside of their immediate worksites or neighborhoods. Researchers should be cognizant regarding the potential for valuable assistance from members who initially appear to be "outside" of a community.

A final comment with respect to community representation is that those interested in engaging in CBPR ought to be as mindful of who can hurt a project as well as who can help. It probably takes less effort to undermine or disrupt a project than to ensure that things move forward smoothly. Ignoring or excluding people, organizations, or agencies, intentionally or not, can have detrimental consequences. Emotions and egos can come into play. For example, one of the authors served on the committee for a recent doctoral study in which the student researcher was having a difficult time recruiting members of the community of interest to participate in an HPV prevention intervention, when a self-proclaimed gatekeeper made an argument for going through her (the gatekeeper) to recruit community members. In the end, the community member contributed very little, but achieved her own goal of gaining control and recognition. CBPR requires thoughtfulness, consideration, and compromise.

Potential Tensions Between Researchers and Community Representatives

Cancer control researchers can expect to encounter some tension with community representatives at different stages throughout a CBPR project. Potentially overlapping sources of tension may exist with respect to community knowledge and community welfare, trust and acceptance in a community, and money and reward structures among the principals involved [16]. Community agencies and individuals can also have different agendas, and occasionally there may be tension between community-based staff and members of the community.

Clearly, there may be tension over what is truly "good" for the community. Discussions over what, how, and/or why can cause tension among and between community members and researchers. Depth of knowledge about history and relations within the community does not always equate with breadth of knowledge or with knowledge about outside political or economic relationships that may affect communities. Knowledge and insight from both insiders and outsiders can complement and supplement each other. Short- and long-term views may also differ and may not always be consistent, practical, or realistic. As mentioned, communities can be quite dynamic over time, both in terms of members and views. Indeed, effectiveness studies with respect to interventions and programs may be time-bound to some degree [17]. So researchers should be familiar with communities beforehand and should avoid relying solely on community representatives for knowledge. This requires spending more "up-front" time in the community, as discussed by Simonds et al. [7] who cited educational programs and pilot studies funded by the National Cancer Institute as effective means of gaining community trust prior to initiating research programs. Again, CBPR is based on collaboration, not reliance or dependence on single viewpoints.

Tension related to trust and acceptance in a community may be natural in social settings. Such tension may be alleviated by spending time in the field. Face-time is particularly important, in that it is often equated as an indicator of investment in a community. Face-to-face discussions are generally more effective at building relationships and creating empathy and understanding than other forms of communication. More extensive interchange is also possible and may increase feelings of individual responsibility and accountability due to the personal touches involved. Trust and acceptance can also be built and fostered by hands-on involvement by the researcher at each stage and level of the project. Researchers can help establish norms and create a tone for the project by setting an example of more than token participation. That is, it may behoove researchers to do some of the project's smaller or day-to-day chores because doing such "little things" adds up and builds personal or project-related capital. The importance of having the ability or perceived credibility of being able to genuinely empathize and relate with residents and staff cannot be overstated. Caring about people matters, and community representatives can recognize if outsiders care.

Of course, money and other rewards can both ease and cause tension as well. Budgets and costs associated with projects can be complicated and confusing to those not directly involved with the financial aspects. Five-hundred thousand dollars in funding may not go nearly as far as the typical community resident might assume.

Money for salaries, incentives, and actual programs is always tight, yet explaining that to those unfamiliar with grants and academic institutions is difficult because the amount of money involved may seem essentially unlimited in their view. Although transparency is the ideal in CBPR, it may be best to avoid talk concerning (or at least avoid casually mentioning) specific dollar amounts for the overall project unless it becomes necessary to do so or unless one has the time for a complete and thorough discussion (e.g., including a question and answer session) of the budgeting process. However, misleading communities about funds is never recommended. Moreover, community representatives and staff members may think academics have the most to gain in executing the research (e.g., more grants, more income, more status, and prestige), which may perhaps cause some resentment or complaining about recognition or pay. Researchers should be aware that respect and status may be more important than money to community members in several instances and respects [18]. In a CBPR project where barbers were trained as prostate cancer peer educators, Luque et al. [19] provided their community partners with a certificate for completing training and recognized the barbers with a plaque that was given at a dinner event.

A final potential tension worth considering concerns one that can develop between a researcher's community-based staff and community members at-large. Staff members may be viewed as being alienated from their own communities because of their collaboration and participation with the project and the investigators. Some residents may feel left out and become jealous or resentful toward the project and may take out their frustrations on staff members. Staff members may occasionally end up in uncomfortable situations in the field. Researchers should consider this and discuss such scenarios with the staff from the outset and throughout the project.

Staffing and Personnel Issues

Time and experience are the major issues with respect to staffing for CBPR projects. The collaboration necessary for CBPR can be time-consuming. Establishing trust and credibility, meetings, accountability processes, and working through crises and conflicts take time. Time management and creating feasible timelines are important because of

deadlines, as is having reasonable expectations, especially of volunteer staff. Researchers occasionally express some impatience regarding CBPR because community members do not donate all of their time and energies to the project. Researchers should understand that community representatives and staff have the same daily constraints as the researchers, e.g., they may have work-related issues to deal with, perhaps on daily basis, such as child care and transportation issues, the need to spend time with families when at home, and church and social obligations. Such issues can be quite disruptive, and some may be more prevalent in low-income communities.

Unfortunate and unexpected events (e.g., funerals, illnesses, transportation problems, other personal crises) also occasionally occur, as well as some positive ones like reunions or celebratory activities.

Work experience is another issue with respect to staffing, and it may often be related to the personal issues mentioned above. Education levels are typically lower and levels of depression are typically higher in low-income communities, both of which are related to workforce quality. Researchers wanting to hire "typical" community members should be aware of potential issues related to work habits and routines. The most employable residents may already have jobs, so many applicants and eventual hires may be working two jobs. It may be best to start with a small staff and build from there. More attention can be given to four staff members than eight, for instance, and good first impressions and work norms may be established more easily and quickly because interactions may be more frequent and monitoring a bit easier.

It is also important to have an honest and open discussion at the start of projects regarding compensation for staff doing fieldwork (e.g., paying per hour or per interview/survey). Monitoring staff is difficult. Employees are typically honest, accountable, and responsible, but a few may overestimate or miscalculate the amount of hours worked if compensated on an hourly basis, and a few may falsify data if compensated on a pay per interview basis. Each project is different, but a discussion and open mind on an appropriate method of compensation is recommended for all. Moreover, some staff members may be uncomfortable handling cash payments to others, due to worries about the consequences of possible losses. Setting up a daily (or weekly) accounting system (i.e., checking out cash at the beginning of the day and checking it back in at closing) can often be helpful to all parties.

Conclusion

We have discussed some practical considerations concerning CBPR with respect to representation, collaboration, and staffing. These concluding remarks are based on our experiences with conducting cancer-related projects in the field. Every project using a CBPR approach will be unique in many ways, even though sharing common ground. Given the diversity of communities and that their leaders, environments, and histories differ, and because CBPR is based on collaboration and possibly compromise at each stage of a project, CBPR projects will differ as well. There are many good reasons the CBPR approach is recommended for cancer prevention and control research with African-Americans. Nevertheless, it is important to be wary of researchers advocating a single "correct" way to implement CBPR. Improving lives should be a major goal of CBPR research, and there may be many responsible ways to do so. Indeed, one of the hallmarks of CBPR is the incorporation of community theories of etiology and change into the empirical science base [5].

Transparency is also critical in conducting CBPR. Being open to community partners matters, but it is just as important to be available. Researchers should not dismiss or underestimate the role of face-time or emotion. When statuses and egos are involved, opinions concerning what constitute minor or major issues or decisions are difficult to predict. Simonds et al. [7] identified some emerging best practices for the future of CBPR within the field of cancer prevention and control. Among these was to recognize the need for positive relationships and trust building in diverse communities and their agencies and organizations. To a large extent, trust depends upon transparency.

Finally, perhaps the most important advice that can be given regarding CBPR is that caring matters. The consequences that occur when community members question whether a researcher cares about others can be severe. Flexibility, transparency, openness, and availability are key for successful CBPR for cancer prevention and control and other chronic disease research with African-American communities.

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