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## Community-Based Research Partnerships: Challenges and Opportunities

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**ABSTRACT** *The complexity of many urban health problems often makes them ill suited to traditional research approaches and interventions. The resultant frustration, together with community calls for genuine partnership in the research process, has highlighted the importance of an alternative paradigm. Community-based participatory research (CBPR) is presented as a promising collaborative approach that combines systematic inquiry, participation, and action to address urban health problems. Following a brief review of its basic tenets and historical roots, key ways in which CBPR adds value to urban health research are introduced and illustrated. Case study examples from diverse international settings are used to illustrate some of the difficult ethical challenges that may arise in the course of CBPR partnership approaches. The concepts of partnership synergy and cultural humility, together with protocols such as Green et al.'s guidelines for appraising CBPR projects, are highlighted as useful tools for urban health researchers seeking to apply this collaborative approach and to deal effectively with the difficult ethical challenges it can present.*

**KEYWORDS** *Community-based participatory research, Ethical issues in research, Participatory action research, Partnership, Urban health.*

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### INTRODUCTION

The complexity of urban health problems has often made them poorly suited to traditional “outside expert”-driven research and intervention approaches.<sup>1</sup> Together with community demands for authentic partnerships in research that are locally relevant and “community based” rather than merely “community placed,” this frustration has led to a burgeoning of interest in an alternative research paradigm.<sup>1,2</sup> Community-based participatory research (CBPR) is an overarching term that increasingly is used to encompass a variety of approaches to research that have as their centerpiece three interrelated elements: participation, research, and action.<sup>3</sup> As defined by Green et al.<sup>4</sup> for the Royal Society of Canada, CBPR may concisely be described as “systematic investigation with the participation of those affected by an issue for purposes of education and action or affecting social change.” The approach further has been characterized as

[A] collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research

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topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities.<sup>5,6</sup>

This article briefly describes CBPR's roots and core principles and summarizes the value added by this approach to urban health research. Drawing on examples from a variety of urban health settings nationally and internationally, it discusses and illustrates several of the key challenges faced in applying this partnership approach to inquiry and action. The article concludes by suggesting that despite such challenges and the labor-intensive nature of this approach, CBPR offers an exceptional opportunity for partnering with communities in ways that can enhance both the quality of research and its potential for helping address some of our most intractable urban health problems.

### **HISTORICAL ROOTS AND CORE PRINCIPLES**

The roots of CBPR may be traced in part to the action research school developed by the social psychologist Kurt Lewin<sup>7</sup> in the 1940s, with its emphasis on the active involvement in the research of those affected by the problem being studied through a cyclical process of fact finding, action, and reflection. But CBPR is most deeply grounded in the more revolutionary approaches to research that emerged, often independently from one another, from work with oppressed communities in South America, Asia, and Africa in the 1970s.<sup>3,8,9</sup> Brazilian adult educator Paulo Freire<sup>9</sup> provided critical grounding for CBPR in his development of a dialogical method accenting co-learning and action based on critical reflection. Freire,<sup>9</sup> Fals-Borda,<sup>10</sup> and other developing countries' scholars developed their alternative approaches to inquiry as a direct counter to the often "colonizing" nature of research to which oppressed communities were subjected, with feminist and postcolonialist scholars adding further conceptual richness.<sup>11,12</sup>

Among the tenets of participatory action approaches to research outlined by McTaggart<sup>13</sup> are that it is a political process, involves lay people in theory-making, is committed to improving social practice by changing it, and establishes "self-critical communities." As Israel et al.<sup>6</sup> adds, other core principles are that CBPR "involves systems development and local community capacity development," is "a co-learning process" to which community members and outside researchers contribute equally, and "achieves a balance between research and action." CBPR reflects a profound belief in "partnership synergy." As described by Lasker et al.<sup>14</sup>:

[T]he synergy that partners seek to achieve through collaboration is more than a mere exchange of resources. By combining the individual perspectives, resources, and skills of the partners, the group creates something new and valuable together—something that is greater than the sum of its parts.

Moreover, CBPR embodies a deep commitment to what Tervalon and Murray-Garcia<sup>15</sup> have called cultural humility. As they point out, although we can never become truly competent in another's culture, we can demonstrate a "lifelong commitment to self evaluation and self-critique," to redress power imbalances and "develop and maintain mutually respectful and dynamic partnerships with communities."<sup>15</sup> Although the term cultural humility was coined primarily in reference to race and ethnicity, it also is of value in helping us understand and address the impacts of professional cultures (which tend to be highly influenced by white, western,

patriarchal belief systems), as these help shape interactions between outside researchers and their community partners.<sup>15</sup>

CBPR is not a method per se but an orientation to research that may employ any of a number of qualitative and quantitative methodologies. As Cornwall and Jewkes<sup>16</sup> note, what is distinctive about CBPR is “the attitudes of researchers, which in turn determine how, by and for whom research is conceptualized and conducted [and] the corresponding location of power at every stage of the research process.” The accent placed by CBPR on individual, organizational, and community empowerment also is a hallmark of this approach to research.

With the increasing emphasis on partnership approaches to improving urban health, CBPR is experiencing a rebirth of interest and unprecedented new opportunities for both scholarly recognition and financial support. In the United States, for example, the Institute of Medicine<sup>17</sup> recently named “community-based participatory research” as one of eight new areas in which all schools of public health should be offering training.

Although the renewed interest in CBPR provides a welcome contrast to more traditional top-down research approaches, it also increases the dangers of co-optation as this label is loosely applied to include research and intervention efforts in search of funding that do not truly meet the criteria for this approach. The sections below illustrate some of the value added to urban research when authentic partnership approaches are taken seriously and then briefly highlight some of the ethical challenges such work may entail.

## **THE VALUE ADDED TO URBAN HEALTH RESEARCH BY A CBPR APPROACH**

CBPR can enrich and improve the quality and outcomes of urban health research in a variety of ways. On the basis of the work of many scholars and institutions,<sup>4,6,8,18</sup> and as summarized by the National Institutes of Health (<http://grants.nih.gov/grants/guide/pa-files/PAR-05-026.html>), some of its primary contributions may be characterized and illustrated as follows.

### **CBPR Can Support the Development of Research Questions that Reflect Health Issues of Real Concern to Community Members**

Ideally, CBPR begins with a research topic or question that comes from the local community, as when the nongovernmental organization (NGO) Alternatives for Community and Environment (ACE) in the low-income Roxbury section of Boston, reached out to Harvard University’s School of Public Health and other potential partners to study and address the high rates of asthma in their neighborhood. Collaborative studies using air-monitoring and other approaches yielded data supporting the hypothesis that Roxbury was indeed a hot spot for pollution contributing to asthma. This in turn paved the way for a variety of policy and community education actions and outcomes.<sup>19</sup>

Although having a community partner such as ACE identify an issue and catalyze a research partnership may be the ideal, it is often the privileged outside researcher who initiates a CBPR project. In these instances too, however, a genuine commitment to high-level community involvement in issue selection, with NGOs and formal and informal community leaders engaged as equal partners, can help ensure that the research topic decided upon really is of major concern to the local population.

**CBPR Can Improve Our Ability to Achieve Informed Consent, and to Address Issues of “Costs and Benefits” on the Community, and not Simply the Individual Level<sup>20</sup>**

With its accent on equitable community involvement in all stages of the research process,<sup>6</sup> CBPR often finds creative means of ensuring informed consent. The “One Hand, One Heart” study in urban and rural Tibet, which included a randomized controlled clinical trial of an indigenous medicine to prevent maternal hemorrhaging, actively involved local midwives and other community partners on the research team who played a key role in helping find locally translatable concepts to improve informed consent. Their help in early ethnographic work thus revealed that the concept of disclosing risk was highly problematic, because such disclosure was believed to disturb the wind element responsible for emotions, potentially leading to emotional upset and other adverse outcomes. By reframing risk disclosure as “safety issues,” needed information could be conveyed in a far more culturally acceptable manner.<sup>21</sup>

CBPR also offers an important potential opening for extending the gaze of our ethical review processes such that we examine and address risks and benefits for the community. In Toronto, Travers and Flicker<sup>20</sup> have pioneered in developing such guidelines, pointing out the importance of having us ask such questions as “Will the methods used be sensitive and appropriate to various communities?” “What training or capacity building opportunities will you build in?” and “How will you balance scientific rigor and accessibility?” The strong philosophical fit between questions such as these and CBPR’s commitments to equitable partnership and community capacity building reflect another source of value added to urban health research through this approach.

**CBPR Can Improve Cultural Sensitivity and the Reliability and Validity of Measurement Tools Through High-Quality Community Participation in Designing and Testing Study Instruments**

Particularly in survey research, community advisory boards (CABs) and other partnership structures can improve measurement instruments by making sure that questions are worded in ways that will elicit valid and reliable responses. In a study of urban grandparents raising grandchildren due to the crack cocaine epidemic, the author and her colleagues used validated instruments, such as those for depressive symptomatology. However, they also learned from CAB members how to word other questions about sensitive topics. Rather than asking a standard (and disliked) question about income, for example, the CAB encouraged us to rephrase the question as “How much money is available to help you in raising this child?” When this alternate wording was used, a wealth of detailed income data was obtained, which improved our understanding of the challenges faced by this population.<sup>22</sup>

**CBPR Can Uncover Lay Knowledge Critical to Enhancing Understanding of Sensitive Urban Health Problems**

Through the cultural humility and partnership synergy involved in deeply valuing lay knowledge and working in partnership with community residents, CBPR can uncover hidden contributors to health and social problems. The high rates of HIV/AIDS in India and the often sensitive nature of this subject among young men led the Deepak Charitable Trust to develop a research committee for a study in the industrial area of Nandesari, in Gujarat, comprised of several male village health

workers and other young men from the area. Working closely with a medical anthropologist, the research committee planned the research, including developing a sampling plan and the phrasing of culturally sensitive questions. Their insider knowledge helped reveal that AIDS itself was not perceived as a major problem by the young men in this area. Instead, men who were engaging in high-risk behaviors wanted to find sex partners at least partly to avoid “thinning of the semen” and sexual dysfunction and fatigue, which were believed to be long-term consequences of masturbation and nocturnal emissions. These fears appeared to be contributing to high rates of unprotected intercourse with sex workers at the area’s many truck stops and with other sex partners.<sup>23</sup> This insider knowledge both strengthened the research and led to subsequent interventions to help dispel such misinformation.

### **By Increasing Community Trust and Ownership, CBPR Can Improve Recruitment and Retention Efforts**

In a participatory epidemiology project on diabetes in an urban Aboriginal community in Melbourne, Australia, a marked increase in recruitment was experienced following the hiring of a community codirector and the changing of the project’s name to one chosen by the local community.<sup>24</sup> Similarly, a 69% response rate achieved in a CBPR study of the health and working conditions of the largely immigrant hotel room cleaner population (many of them undocumented) in several of San Francisco’s major tourist hotels was heavily attributed to the hiring and training of a core group of 25 room cleaners as key project staff. That high response rate, together with the high quality of data collected, made a substantial contribution when results later were presented and used to help negotiate a new contract.<sup>25</sup>

### **CBPR Can Help Increase Accuracy and Cultural Sensitivity in the Interpretation of Findings**

Even highly engaged community members of the research team may not wish to be involved in the labor-intensive data analysis phase of a research project,<sup>26</sup> nor do all methodological approaches lend themselves to such involvement. Yet when applicable and desired, community involvement in data analysis can make real contributions to our understanding of the themes and findings that emerge. In a US study of and with people with disabilities on the contentious topic of death with dignity legislation in their community, the author and an “insider/outsider” member of research team met on alternate Saturdays with a subcommittee of the CAB to engage in joint data analysis. Using redacted transcripts, and applying lessons learned in qualitative data interpretation, the diverse CAB members came up with far richer codes and themes than outside researchers could have achieved alone.<sup>27</sup>

### **CBPR Can Increase the Relevance of Intervention Approaches and Thus the Likelihood of Success**

One of the strengths of CBPR is its commitment to action as part of the research process. But without strong community input, researchers not infrequently design interventions that are ill suited to the local context in which they are applied. In the Gujarat case study mentioned above, partnership with local community members helped in the design of culturally relevant interventions, such as street theater performed by locally recruited youth at *melas* (or fairs), and the dissemination of study findings through the 15 local credit and savings groups that often provided platforms for discussing reproductive health and related issues. Both these approaches provided critical means of information dissemination on this culturally and emotionally charged topic.<sup>23</sup>

## **ETHICAL AND OTHER CHALLENGES IN COMMUNITY-BASED PARTICIPATORY RESEARCH**

Engaging in urban health research with diverse community partners can indeed enrich both the quality and the outcomes of such studies. At the same time, CBPR is fraught with ethical and related challenges, several of which are now highlighted.

### **“Community Driven” Issue Selection**

A key feature of CBPR involves its commitment to ensuring that the research topic comes from the community. Yet many such projects “paradoxically . . . would not occur without the initiative of someone outside the community who has the time, skill, and commitment, and who almost inevitably is a member of a privileged and educated group.”<sup>28</sup> In such instances, outside researchers must pay serious attention to community understandings of what the real issue or topic of concern is.

In South Africa, for example, high rates of cervical cancer in the Black and Colored populations led Mosavel et al.<sup>29</sup> to propose an investigation of this problem. In response to community feedback, however, they quickly broadened their initial topic to “cervical health,” a concept which “acknowledged the fact that women’s health in South Africa extends well beyond the risk of developing cervical cancer, and includes HIV-AIDS and STDs, sexual violence, and multiple other social problems.” In other instances, the outside researcher as an initiator of a potential CBPR project needs to determine whether the topic he or she has identified really is of concern to the local community—and whether outsider involvement is welcome. The Oakland, California-based Grandmother Caregiver Study mentioned above grew out of the interests of my colleague and I in studying the strengths of as well as the health and social problems faced by the growing number of urban African American grandmothers who were raising grandchildren in the context of a major drug epidemic. As privileged white women, however, we had to determine first whether this was a topic of local concern and, if so, whether there might be a role for us in working with the community to help study and address it. We began by enlisting the support of an older African American colleague with deep ties in the community, who engaged with us in a frank discussion with two prominent African American NGOs. It was only after getting their strong support for proceeding that we wrote a grant, with funds for these organizations, which in turn helped us pull together an outstanding CAB that was actively involved in many stages of the project.<sup>21,26</sup>

We were lucky in this case that a topic we as outsiders identified turned out to represent a deep concern in the local community. Yet not infrequently “the community” is in fact deeply divided over an issue. Indeed, as Yoshihama and Carr<sup>30</sup> have argued, “communities are not places that researchers enter but are instead a set of negotiations that inherently entail multiple and often conflicting interests.” In such situations, outside researchers can play a useful role in helping community partners think through who “the community” in fact is in relation to a proposed project and the pros and cons of undertaking the project to begin with. The holding of town hall meetings and other forums may then be useful in helping achieve consensus on an issue that is truly of, by, and for the community, however it is defined.<sup>26</sup>

### **Insider–Outsider Tensions**

Urban health researchers in many parts of the world have written poignantly about the power dynamics and other sources of insider–outsider tensions and misunderstandings in CBPR and related partnership efforts. Ugalde<sup>31</sup> points out how in Latin

American participants may be exploited as cheap sources of labor or may become alienated from their communities because of their participation. In her work with Native American and other marginalized groups in New Mexico, Wallerstein<sup>32</sup> further illustrates how even outsiders who pride ourselves on being trusted community friends and allies often fail to appreciate the extent of the power that is embedded in our own, often multiple sources of privilege, and how it can affect both process and outcomes in such research.

One major source of insider–outsider tensions involves the differential reward structures for partners in CBPR. For although a major aim of such research is to benefit the local community, the outside researchers typically stand to gain the most from such collaborations, bringing in grants, getting new publications, and so forth. The common expectation that community partners will work for little or no pay and the fact that receipt of compensation may take months if the funds are coming through a ministry of health or a university are also sources of understandable resentment.<sup>6,26</sup>

To address these and other sources of insider–outsider tensions in work with indigenous communities in both urban and rural areas, researchers in New Zealand,<sup>33</sup> Australia,<sup>34</sup> the United States,<sup>35</sup> and Canada<sup>36</sup> have worked with their community partners to develop ethical guidelines for their collaborative work, including protocols that address

- (1) negotiating with political and spiritual leaders in the community to obtain their input and their approval for the proposed research,
- (2) ensuring equitable benefits to participants (e.g., appropriate training and hiring of community members) in return for their contributions and resources
- (3) developing agreements about the ownership and publication of findings, and the early review of findings by key community leaders.

Although such protocols cannot begin to address all of the conflicts that may arise in CBPR, they can play a critical role in helping pave the way for the continued dialogue and negotiation that must be an integral part of the process.

### **Constraints on Community Involvement**

Outside researchers committed to a CBPR approach not infrequently express frustration at the difficulty moving from the goal of heavy community partner involvement in the research process to the reality. As Diaz and Simmons<sup>37</sup> found in their Reproductive Health Project in Brazil, despite a strong commitment to involving the most marginalized and vulnerable classes (in this case, women who were users of the public sector services being studied), such individuals often “are least likely to be in a position to donate their time and energy.” Further, and even when outside researchers are careful to provide child care and transportation, there are differential costs of participation by gender.<sup>30</sup>

Still another set of challenges may arise when community desires with respect to research design and methods clash with what outsider researchers consider to be “good science.” In an oft-cited CBPR study with a local Mohawk community in Québec, Chataway<sup>38</sup> describes how community members at first strongly objected to the idea of using a questionnaire approach which they saw as “putting their thoughts in boxes.” Through respectful listening on both sides, the value of such an approach was realized and a more qualitative methodology developed, through

which community members would then be actively involved in helping analyze and interpret the quantitative findings that emerged. As such case studies illustrate, CBPR does not condone an abandonment of one's own scientific standards and knowledge base. But it does advocate a genuine co-learning process through which lay and professional ways of knowing both are valued and examined for what they can contribute.<sup>26</sup>

### **Dilemmas in the Sharing and Release of Findings**

A crucial step in CBPR involves returning data to the community and enabling community leaders and participants to have an authentic role in deciding how that data will be used. As Travers and Flicker<sup>20</sup> suggest, ethical research review processes that ask questions such as "Are there built-in mechanisms for how unflattering results will be dealt with?" should be employed at the front end of our CBPR projects. In addition to the formal IRB process they propose, which offers a critical next step for the field, CBPR partners can look to a variety of formal or informal research protocols and particularly to the detailed guidelines for health promotion research developed by Green et al.,<sup>4,39</sup> which help partnerships decide in advance how potentially difficult issues concerning the sharing and release of findings and other matters will be handled.

### **Challenges in the Action Dimensions of CBPR**

Numerous ethical challenges lastly may arise in relation to the critical action component of CBPR. In some instances, community partners may wish to move quickly into action, whereas academic and other outside research partners may want to "put the breaks on" until findings have been published or other steps brought to fruition. In other cases, the nature of funding (e.g., from a government body) may constrain action on the policy level that is prohibited or discouraged by the funder. And in still other instances, including the Brazilian Reproductive Health Project<sup>37</sup> cited above, community members may not wish to be associated with a CBPR project that appears connected to a broader political agenda.

Participation in the action phase of CBPR projects may sometimes present risks to community participants, as when immigrant hotel room cleaners in the San Francisco study took part in a Labor Day sit-in and in some cases faced arrest.<sup>25</sup> And for both professionally trained researchers and their community partners, actions that involve challenging powerful corporate or other entrenched interests may have negative consequences for those involved. At the same time, CBPR's fundamental commitment to action and to redressing power imbalances makes this aspect of the work a particularly important contributor to urban health improvement through research.

## **CONCLUSION**

Difficult ethical challenges may confront urban health researchers who engage in CBPR. Yet this approach can greatly enrich the quality of our research, helping ensure that we address issues of genuine community concern and use methods and approaches that are culturally sensitive and that improve the validity and reliability of our findings. Moreover, through its commitment to action as an integral part of the research process, CBPR can help in translating findings as we work with community partners to help address some of our most intractable urban health problems.

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