

# Ethical Challenges for the “Outside” Researcher in Community-Based Participatory Research

Meredith Minkler, DrPH

Although community-based participatory research (CBPR) shares many of the core values of health education and related fields, the outside researcher embracing this approach to inquiry frequently is confronted with thorny ethical challenges. Following a brief review of the conceptual and historical roots of CBPR, Kelly's ecological principles for community-based research and Jones's three-tiered framework for understanding racism are introduced as useful frameworks for helping explore several key challenges. These are (a) achieving a true “community-driven” agenda; (b) insider-outsider tensions; (c) real and perceived racism; (d) the limitations of “participation”; and (e) issues involving the sharing, ownership, and use of findings for action. Case studies are used in an initial exploration of these topics. Green et al.'s guidelines for appraising CBPR projects then are highlighted as an important tool for helping CBPR partners better address the challenging ethical issues often inherent in this approach.

**Keywords:** *community-based participatory research; research ethics; community partnerships*

With its commitments to education, strengths-based approaches to individual and community capacity building<sup>1-3</sup> and action as part of the research process, community-based participatory research (CBPR) represents an orientation to inquiry that is highly consistent with the principles of health education and “public health as social justice.”<sup>4</sup> A partnership approach that breaks down the barriers between the researcher and the researched<sup>5</sup> and values community partners as equal contributors to the research enterprise, CBPR also underscores ethical principles such as self-determination, liberty, and equity and reflects an inherent belief in the ability of people to accurately assess their strengths and needs and their right to act upon them.<sup>6</sup>

Yet even when the principles of CBPR are followed, difficult ethical issues often arise that must be sensitively addressed. Following a brief review of CBPR and its conceptual

---

Meredith Minkler, DrPH Program, School of Public Health, University of California, Berkeley.

*Address reprint requests to* Meredith Minkler, DrPH Program, School of Public Health, University of California, Berkeley, Earl Warren Hall Room 316, UC Berkeley, Berkeley, CA 94720-7360; phone: (510) 642-4397; fax: (510) 643-8236; e-mail: [mink@uclink.berkeley.edu](mailto:mink@uclink.berkeley.edu).

Many thanks are extended to my current and former community and academic partners, and to my graduate students, for the many helpful (and sometimes difficult) discussions that continue to contribute to my own learning and critical reflections on community-based participatory research (CBPR). Thanks also are due my friend and colleague James G. Kelly for sharing his insights based on decades of work in the field. Finally, my gratitude is extended to Gena Anderson for assistance with manuscript preparation and to the editor and anonymous reviewers whose helpful suggestions on an earlier draft greatly improved the article.

*Health Education & Behavior*, Vol. 31 (6): 684-697 (December 2004)

DOI: 10.1177/1090198104269566

© 2004 by SOPHE

684

roots and underlying principles, the ecological principles and premises developed by community psychologist James G. Kelly<sup>7,8</sup> and Kelly and colleagues<sup>9</sup> will be presented and used as a conceptual framework for exploring several of the key ethical challenges faced by the “outsider” in CBPR. Additional concepts, key among them physician and epidemiologist Camara Jones’s<sup>10</sup> three-tiered framework for understanding racism, also will be employed for the additional light they may shed on several of these ethical challenges. The topics explored include (a) achieving a true “community-driven” agenda when the outside professional is the project catalyst or initiator; (b) insider-outsider tensions that arise in relation to differential race, power, time constraints, and reward structures for such undertakings; (c) racial/ethnic and cultural issues including real and perceived racism; (d) challenges concerning the limitations of “participation”; and (e) issues involving the sharing, ownership, and use of findings for action. Although space constraints preclude a detailed look at all of the dimensions of each of these challenges, illustrations from contemporary case studies are presented and analyzed to provide an introductory look at the overarching issues discussed, as a stimulus to further dialogue. The article will conclude with implications for practice, including the utility of the guidelines for appraising CBPR projects developed by Green and his colleagues<sup>11</sup> in helping outsiders and their community partners address these and other challenging issues.

## BACKGROUND

CBPR is an overarching term that increasingly is used to encompass a variety of approaches to research, such as collaborative inquiry, participatory action research (PAR), feminist participatory research, and action research.<sup>6</sup> Although differing in their goals and change strategies, these approaches may be seen to share a set of core values and principles<sup>12</sup> and have as their centerpiece three interrelated elements: participation, research, and action.<sup>13</sup> As summarized by Israel and her colleagues,<sup>3</sup> the fundamental principles of such research are that

- it is participatory;
- it is cooperative, engaging community members and researchers in a joint process to which each contributes equally;
- it is a colearning process;
- it involves systems development and local capacity building;
- it is an empowering process through which participants can increase control of their lives; and
- it achieves a balance between research and action.

As suggested above, 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>5</sup> note, what is distinctive about CBPR “is not the methods used but methodological contexts of their application”; what is new 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” (p. 1667). The accent placed in CBPR on individual, organizational, and community empowerment, involving “participation, control and critical awareness” at each of these levels<sup>14</sup> also is a hallmark of this approach to research.

For the purposes of this article, and drawing on the work of Israel and her colleagues<sup>3</sup> and Green et al.,<sup>11</sup> CBPR is defined 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 topic of importance to the community with the aim of combining knowledge and action for social change

to improve health and human welfare.<sup>15</sup> Explicit throughout the CBPR process are the deconstruction of power and the democratization of knowledge<sup>16</sup> such that the experiential knowledge of community members is valued and knowledge that previously was the purview of scholars is accessible physically and intellectually to community participants, as well as being relevant to their needs and concerns.

The approaches to inquiry known as CBPR are rooted in two distinct but interrelated traditions: the action research school developed by social psychologist Kurt Lewin<sup>17</sup> in the 1940s and the more revolutionary alternative 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>13,18-21</sup> From Lewin's work, CBPR takes its emphasis on the active involvement in the research of those affected by the problem under study through a cyclical process of fact finding, action, and reflection, leading to further inquiry and action for change. The work of Brazilian adult educator Paulo Freire similarly provides critical grounding for CBPR, in its development of a dialogical method accenting colearning and action based on critical reflection.<sup>21</sup> Freire,<sup>21</sup> Fals-Borda,<sup>19</sup> and other third world scholars developed their revolutionary approaches to inquiry as a direct counter to the often "colonizing" nature of research to which oppressed communities were subjected. Later contributions of feminist researchers<sup>22</sup> and poststructuralists and postcolonialists (who attempt to surface and give primacy to "community narratives" and explanations of their life conditions<sup>23,24</sup>) further built on this alternative research tradition and provided additional conceptual richness.

With the increasing emphasis on partnership approaches to improving community health and welfare, CBPR is experiencing a rebirth of interest and unprecedented new opportunities for both scholarly recognition and financial support. In the health field, the Institute of Medicine<sup>25</sup> recently named community-based participatory research as one of eight new areas in which all schools of public health should be offering training, and the Centers for Disease Control and Prevention (CDC) has mounted a major new funding initiative in this area. The Research Triangle Institute–University of North Carolina Evidence-Based Practice Center recently completed a comprehensive study of the evidence base for CBPR in public health,<sup>26</sup> commissioned by the Agency for Healthcare Research and Quality (AHRQ). The latter organization also sponsored a special issue of the *Journal of General Internal Medicine*<sup>27</sup> on this approach. Finally, organizations like Community Campus Partnerships for Health (<http://www.futurehealth.ucsf.edu/ccph.html>) have been among those working actively to help develop new standards for engaged scholarship so that faculty members who undertake research with community partners are not penalized by a university reward system that has tended to devalue such collaborative endeavors.<sup>28,29</sup>

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 and that are more truly "community placed" than "community based." Within this context, it becomes increasingly imperative to underscore the key elements of the authentic partnerships approaches characterized by CBPR and to explore the many ethical challenges that such work may entail.

## CONCEPTUAL FRAMEWORK

Almost 40 years ago, community psychologist James G. Kelly<sup>7,30</sup> developed his ecological orientation to prevention, emphasizing the interdependence of persons and their social environments. In subsequent work, Keller and his colleagues<sup>9</sup> suggested that the quality of findings in areas such as CBPR is “directly and immeasurably affected by the processes and actions when beginning and maintaining a working relationship between professionals and citizens” (p. 348). Kelly also posited that an ecological approach involves “adapting the research enterprise to the culture and context of the participants” (p. 348)<sup>9</sup> and preserving and contributing to individual and community resources.<sup>7</sup> He further argued that the quality of the research relationship would affect each stage of the process up to and including the use of findings for action. Finally, he stressed the importance of identifying “the points of policy impact before the research begins” and of carefully attending to potential side effects of participation as critical to the research enterprise<sup>7</sup> (pp. 8-9).

Complementing Kelly’s premises and principles, and of particular importance in CBPR partnerships characterized by deep cultural divides between outside researchers and community members, is a second conceptual approach: Camara Jones’s<sup>10</sup> three-tiered framework for understanding racism. Briefly, as Jones notes, racism may be *institutionalized* (manifesting in access to power and material conditions), *personally mediated* (encompassing prejudice and discrimination based on stereotypic race-based assumptions and judgments), or *internalized* (reflected in people’s own acceptance of negative messages concerning their own race or ethnic group). As Vivian Chavez and her colleagues<sup>31</sup> point out, and as demonstrated later in this article, “The interaction of institutionalized racism, personally mediated racism and internalized racism produces a climate that can manifest itself in CBPR” with unfortunate consequences (p. 84). Together with related concepts described below, including historical trauma<sup>32,33</sup> and cultural humility,<sup>34</sup> Jones’s typology is used, with Kelly’s ecological premises and principles, to foster a beginning dialogue on, and exploration of, five ethical challenges commonly faced in CBPR.

## “COMMUNITY-DRIVEN” ISSUE SELECTION

A key distinguishing feature of CBPR involves its commitment to ensuring that the topic to be investigated comes from the community.<sup>18,35</sup> Yet as Peter Reason<sup>36</sup> has pointed out, many such projects “paradoxically . . . would not occur without the initiative of someone with time, skill, and commitment, someone who will almost inevitably be a member of a privileged and educated group” (p. 334).

Can true CBPR take place when the research question itself comes from an outsider to the community? Sociologist Randy Stoecker<sup>35</sup> answers cautiously in the affirmative, noting that the “initiator” is one of several roles outside academics usefully can play in the participatory research process. Yet he points to the critical need for skills in community organizing and group dynamics if the outsider is to be successful in helping shift control to the community.

When the topic for a potential research partnership does come from an outsider, a key preliminary step should involve determining whether the proposed subject really is high on the agenda of the affected community. As Kelly et al.<sup>9</sup> suggest, the role of a liaison person who can serve as a “boundary spanner” and mediator helping in the definition of

mutual goals can be critical in this and subsequent stages of the research. The wisdom of Kelly's emphasis on the critical initiation phase of CBPR, and on the usefulness of a community liaison to facilitate early interactions, was demonstrated for my colleague, Kathleen Roe and I, in the Grandparent Caregiver Study that was carried out in Oakland, California, during the crack cocaine epidemic in the early 1990s. When we first became interested in the problems and strengths faced by African American grandparents raising grandchildren in the context of the epidemic, we questioned whether as White women, privileged in terms of education and socioeconomic status, we should even hope to play a role in helping study this sensitive topic. We therefore began by enlisting the support of a liaison person—an older colleague with deep roots in the local African American community. With her as our “cultural guide,” we met with two prominent African American community-based organizations (CBOs) to ask whether the issue was indeed of concern to the local community, and if so, whether we as outsiders, together with some interested African American graduate students, might play a role helping to study it. On receiving an enthusiastic response, we wrote a grant proposal that included funds for these organizations, which in turn assisted us in putting together a strong community advisory board (CAB). The latter's extensive participation in phrasing the interview questions, sampling considerations, dialoging about the findings, returning findings to the community, and using the results as the basis of action greatly enhanced both the quality of the findings achieved and their application for social change.<sup>37</sup>

The Grandparent Caregiver Study, which helped to catalyze several years of subsequent action with and by local community partners (e.g., in the formation of a regional coalition that worked for legislative change), provides an example of how a topic that originates with the interests of outside researchers can nevertheless become “owned” by the community so that the resulting project truly reflects their interests and concerns. Yet as Labonté points out, “communities are not homogenous,” and not infrequently in such collaborations, “the community” is, in fact, deeply divided over an issue.<sup>38</sup> Outside researchers therefore must take particular care in helping community partners think through the pros and cons of undertaking the project to begin with.

On one hand, CBPR lends itself to the study of controversial issues, because through dialogue and critical reflection, hard issues can receive the benefit of open and frank scrutiny and debate.<sup>39</sup> On the other hand, however, because CBPR is committed in part to strengthening community capacity and trust, choosing as an issue a topic that may further divide community members may hold considerable risk. In such instances, as Kelly et al.<sup>9</sup> suggest, the ethical premise underlying topic selection may be that “ecological research preserves and enhances . . . [the community's] natural human resources” (p. 349). Particularly in low-income communities of color and other disenfranchised groups, the importance of achieving consensus on an issue that is truly of, by, and for the community should be underscored, and approaches, such as focus groups and town hall meetings, should be employed to help facilitate this process.

### INSIDER-OUTSIDER TENSIONS

Power dynamics and other sources of insider-outsider tensions and misunderstandings in CBPR have been widely discussed in the literature.<sup>12,39,40</sup> As noted below, such tensions may have multiple immediate or surface causes. Yet often underlying them, particularly in cross-cultural research, are far deeper and more complex issues. The concept of historical trauma,<sup>32,33</sup> for example, has been used, especially in relation to Native Ameri-

can and African American communities, to explicate how the assaults visited on earlier generations (e.g., colonization and slavery) may have physical and mental health effects on subsequent generations, contributing to health disparities. As Chavez and her colleagues<sup>31</sup> note, historical trauma, together with internalized oppression (people's acceptance of the negative messages they receive about their own race or ethnicity) and institutional and personally mediated racism,<sup>10</sup> may contribute to "a dialectic of resistance between outsider research partners and community participants with very real ethical dilemmas in speaking truth to power" (p. 87).

A useful case study in this regard may be found in health education professor Nina Wallerstein's<sup>12</sup> frank and detailed look at how her efforts to engage in a truly participatory evaluation of New Mexico's Healthier Communities Initiative were compromised by her failure to adequately assess the sources and extent of community distrust in this situation. Native coalition members' perceptions of the "weight of authority" she carried as a university faculty member, a dominant culture urban White, and the recipient of a large grant from the Department of Health, thus led to her being perceived as "having power to potentially control how the 'state' directed their work" (p. 48). As a consequence, Wallerstein notes, participation in the project was perceived as not truly voluntary, and resistance (e.g., in an "unwillingness to subject the coalition to critical scrutiny" about their adherence to healthier communities principles) was encountered (p. 48). Although this project had a fortunate outcome, helping to catalyze the partners' development of the widely used *Evaluation Workbook for Community Initiatives*,<sup>41</sup> it stands as an important example of the room for misunderstanding and tensions even in situations in which there is a long history of trust and collaboration between community and outside research partners.

Layered on more deep-seated sources of insider-outsider tensions are those that arise around the often substantial differences in the timetable and priority ascribed to the research by community and outside research partners. As Stoecker<sup>35</sup> and others<sup>39,42</sup> suggest, genuine collaboration takes not insignificant amounts of time, for meetings, accountability processes, and for working through conflicts. Such time may be in especially "short supply" for community partners.

Still another source of insider-outsider tensions involves the differential reward structures for partners in CBPR. As Kelly<sup>7</sup> and others<sup>1,3,13</sup> suggest, a major aim of such research is to benefit the local community by providing new information on a topic of concern, increasing human resources, and including action to help redress the problem (and ideally facilitate social change) as an integral part of the research process. Despite these laudable goals, however, community partners not infrequently perceive that it is the academic or professional researchers who stand to gain the most from such collaborations, bringing in grants (often with salary support), adding to their publication lists, and so forth. The common expectation that community partners will work in a minimally paid capacity and the fact that receipt of compensation may take months if the funds are coming through university or other large bureaucratic systems understandably may be sources of considerable resentment and frustration.<sup>3,42,43</sup> Substantially increasing the funding allocated for community partners and working with CBOs to enhance their fiduciary capacity so that they can themselves become fiscal agents on future CBPR grants<sup>3,43</sup> are among the recommendations that have been put forth to help address such concerns. In addition, increased success has been demonstrated in partnership efforts that have had access to flexible, discretionary dollars or "braided funding streams,"<sup>44</sup> enabling the funding of new activities based on emerging community needs and not tied to rigid budgets created before the project began.



Through these and other means, outside researchers can help minimize some of the causes of insider-outsider tension that frequently hamper participatory research efforts. As noted above, however, such sources of tensions are often simply surface manifestations of far deeper concerns. As Wallerstein<sup>12</sup> reminds us, “only through engaging in open dialogue about the inequities and hidden nature of power, can the relationship become reciprocal and ultimately transformed” (p. 49).

### RACISM AND CULTURAL HUMILITY

In the United States, as in many parts of the world, CBPR has tended to involve work with and by low-income communities, which tend to be disproportionately communities of color.<sup>6</sup> Because the outside researchers in CBPR partnerships frequently do not share the race, ethnicity, or culture(s) of their community partners, opportunities for cultural misunderstandings and for real or perceived racism are often substantial. For activist Makani Themba,<sup>45</sup> “racism is like the gorilla in the living room. It’s running through the place, making noises, and everyone is trying to sit politely and ignore it” (p. 92). Jones’s<sup>10</sup> three-tiered framework of *institutionalized*, *personally mediated*, and *internalized* racism is helpful for deconstructing, understanding, and confronting difficult situations in CBPR in which “the gorilla” is present, often in multiple forms, yet typically not acknowledged.

One such deeply troubling situation occurred for the author when I was hired as a research consultant to help a nonprofit organization design and conduct a participatory evaluation of a large community health intervention project. The organization’s staff had put together an impressive-sounding CAB, including program participants, researchers, and high-level administrators. Because the topic area of this study was outside my area of expertise, I did not recognize many of the names involved but was pleased when I walked into the first advisory committee meeting to see that most of the members, including the high-level administrators, were, in fact, people of color. Unfortunately, however, all but one of the researchers on the CAB were White, so when my time came to lead a discussion on the research objectives, survey instrument, and analysis plan, the conversation was quickly dominated by the White members present.

Although no one brought this awkward dynamic up at the meeting, several written evaluations suggested that members had indeed been disturbed by what had transpired, and one individual used the word *racist* in his or her comments. Upon learning from staff of these concerns, I consulted a member of the CAB who was particularly knowledgeable about racism and cultural miscommunication. With her support, and the staff’s approval, I then called other members of the committee to sincerely apologize for my role in this situation and to try to engage them in a conversation about how such occurrences could be prevented in the future. Although a few members were eager to talk, others changed the subject or said that nothing had happened.

In retrospect, all three forms of racism may have been present in this situation. *Institutionalized racism* severely limited the number of highly trained researchers of color who might otherwise have been available for participation in a study like this one. *Personally mediated racism* was reflected in my own inability to immediately recognize and effectively deal with the one-sided nature of the conversation that took place. And finally, *internalized racism* may also have been at work. As an outsider, it is difficult for me to place myself in the shoes of the participants of color who reported seeing no problem with what transpired. Jones’s framework would suggest that for some, however, not noticing, acknowledging, or appearing concerned by the White-dominated nature of the discussion

and project decision making that ensued may well have reflected a deeper dynamic. The “gorilla in the living room” is hard to talk about, but those of us working cross-culturally in CBPR partnerships need to be aware of the potential for all three forms of racism and to have what physician Melanie Tervalon and public health leader Jane Murray-Garcia<sup>34</sup> call “cultural humility” as we try to navigate this difficult terrain. As they point out, although none of us can truly become “competent” in another’s culture, we can approach cross-cultural situations with a humble attitude characterized by reflection on our own biases and sources of invisible privilege, an openness to the culture and reality of others, and a willingness to listen and continually learn.

Approaching our work with cultural humility also means supporting partners of color in the often difficult roles they are likely to play as “outsiders within.” The need for such support was well demonstrated recently in an ambitious CBPR project addressing asthma in a low-income and largely minority community in Seattle, Washington. As part of its multifaceted Seattle Partners for Healthy Communities project, the local health department took care to develop a crossover study for the asthma project: The control households, rather than getting nothing at all, received a less intensive form of the intervention initially and then the full intervention, including home assessments, within a year. Unfortunately, however, it fell to some of the community partners—trained Community Health Workers (CHWs), many of whom “have personal relationships or community connections with participants,” to explain to some unhappy control group members why they were not receiving the full intervention from the very beginning.<sup>43</sup> Kelly’s principle underscoring the need to develop research procedures for carefully studying and monitoring side effects is relevant here, as the costs to CHWs of their participation in this instance may have been substantial. Furthermore, and taking a cue from Paulo Freire,<sup>21</sup> a critical challenge for outsiders in CBPR projects involves helping to ensure that such community partners do not become strangers in their own communities. In efforts like the Seattle asthma project, holding town hall meetings and other forums in which outside researchers can be present to help explain the study strategy and “take the heat” if necessary is important both ethically and in terms of maintaining the goodwill needed to enable such research to continue. As Kelly<sup>7</sup> further suggests, however, before such dynamics can even be understood, the local contexts in which insiders (and outsiders within) operate, and how these contexts in turn affect “the processes of empirical inquiry and collaborative work,” must be carefully and collaboratively studied as well.

## PARTICIPATION AND ITS LIMITATIONS

CBPR’s commitment to high-level community participation throughout the research process raises difficult ethical and practical challenges, beginning with the question of who truly represents “the community.” In contrast to popular definitions of community based on shared geography, demographic characteristics, or sense of identity and common interests, academic social work professor Mieko Yoshihama and her former doctoral student E. Summerson Carr<sup>46</sup> argued that “communities are not places that researchers enter but are instead a set of negotiations that inherently entail multiple and often conflicting interests” (p. 99). The Hmong Women’s Project in a large midwestern city, a feminist participatory action research effort that they initiated, well illustrates this perspective. When a variety of factors, including extensive mobility and close contacts with family across city and state lines, thwarted their efforts to adequately capture “the Hmong community,” these outside partners asked study participants to define the term. *The commu-*



nity was defined very differently depending on the background and circumstances of the persons with whom the outside researchers spoke, with strong divides on the basis of religion, urban-suburban residence, level of assimilation, and gender among the factors helping to shape and determine the definitions of community put forth.

The academic partners in this collaborative study also discovered that, like notions of “community,” “the parameters of . . . what counts for participation are inherently unstable, requiring constant negotiation of ideas, values, identities and interests among all who participate” (p. 85).<sup>46</sup> Hmong women were involved in this project in part through a series of participatory workshops, in which they used photovoice<sup>47</sup> and critical dialogue to significantly expand the topic of interest (from domestic violence to women’s safety and well-being) and then plan for and implement a new CBO to help them address these concerns. The outside researchers’ efforts to promote maximum community participation well reflected Kelly’s concern with “adapting the research enterprise to the culture and context of the participants” (p. 348).<sup>9</sup> Careful attention thus was paid to site selection, providing culturally appropriate food and child care, hiring a community resident to help with recruitment, extensive outreach, and conducting the workshops in Hmong rather than English. Although these efforts succeeded overall, particularly early on in the project, participation tended to be fluid, with conflicting personal and family issues and priorities frequently meaning that different women (albeit often related through family and friendship networks) would attend each meeting. Such fluidity in participation clearly challenges efforts to reach consensus and to build in continuity in the traditional sense. Again, however, an ecological perspective is valuable here: In communities characterized by flux and movement, our notions of participation similarly must be flexible enough to take into account the culture and social environment of the community members with whom we work and to reflect critically on our own role as outside researchers in relation to them.

A thorough discussion of all of the dimensions of participation that raise vexing challenges for the outside researcher is beyond the scope of this article, and readers are directed to the work of Kelly,<sup>7,9</sup> Green and Mercer,<sup>1</sup> Maguire,<sup>22</sup> Wallerstein,<sup>12</sup> and others,<sup>3,43</sup> for a more in-depth look at this area. Green and Mercer, for example, make a case for broadening participation to include a variety of stakeholders, rather than solely community members. Similarly, and building on Aiwā Ong’s<sup>48</sup> reminder that within every Third World there’s a First World, Wallerstein and Duran<sup>49</sup> (p. 34) urge us to question the common practice of seeking service providers in CBOs to serve as the sole community representatives on advisory boards in CBPR projects. With Green and Mercer,<sup>1</sup> they would have us reflect carefully on the question, “If stakeholders reflect people who have the power base of the First World, are they appropriate to fully represent local community residents?”<sup>41</sup>

An in-depth look at the ethical challenges embedded in CBPR’s commitment to participation would include as well grappling with the problems that may arise when community desires with respect to research design and methods bump up against what outside researchers consider to be “good science.” For although CBPR involves “broadening the bandwidth of validity”<sup>50</sup> to include, for example, the validity or usefulness of topic selection from a community perspective, it should not mean lessening our concern with adherence to basic commitments to scientific rigor and to methods for achieving valid and reliable findings. Israel et al.’s<sup>3</sup> notion of “*equitably* involving all partners” and “appreciating the unique strengths each brings” to the CBPR process is helpful here, as are colearning workshops and constant dialogue about decision making and the rationale behind the use of particular methodological approaches and related issues. Engaging in CBPR does not

mean leaving one's own scientific standards and knowledge base at the door but rather sharing one's own "unique gifts," including one's skills as a research methodologist, while accepting the gifts of others through a genuinely reciprocal learning process.<sup>3,43,51</sup>

### SHARING FINDINGS AND GETTING TO ACTION

A fundamental tenet of CBPR involves its commitments to giving the study findings back to the community and facilitating strong community involvement in decision making about the use of those findings for action and social change.<sup>13,16</sup> Although such commitments may seem ethically above reproach, however, each may raise difficult dilemmas for the outsider as research partner. In the Grandparent Caregiver Study mentioned earlier, the sharing of study findings at a luncheon attended by all but 2 of the 71 study participants helped validate our hope that the findings had indeed captured the primary themes and issues articulated by the women. The sharing of initial findings further led to an animated discussion about follow-up actions that could use the study results to help influence policy, to promote physician and public education, and so forth. But the women also expressed concern that one of the smaller findings could do harm to the community should it become public, particularly if it came to the attention of the conservative state governor. Although many academicians argue that scientists have a duty to make all of their findings public, the value base underlying CBPR suggests that our primary responsibility is to the community.<sup>6,13</sup> The outside members of the research team therefore agreed that this particular finding would not be published.<sup>37</sup>

As academics, we were fortunate that the finding in question was a relatively minor one. But suppose a major study result emerges that the community then wishes to suppress? To avoid such difficult situations, many CBPR projects now use formal or informal research protocols and memorandums of understanding<sup>3,52,53</sup> to decide in advance how these and other issues will be handled. In other cases, informal understandings may be worked out early in the process, for example, with the community agreeing to the publication of results even if they do not support the position that that community or agency partner hopes will be strengthened through the study findings.<sup>54</sup> Whether through formal written documents or informal dialogue, however, the importance of grappling with such issues in the earliest stages of a CBPR project cannot be overstressed and relates to the principles of both building and maintaining a good working relationship between professionals and community participants and carefully attending to the potential side effects of the research enterprise.<sup>7,9</sup>

A final set of ethical challenges and dilemmas involve the action component of CBPR projects, which may take a wide variety of forms. Kelly's<sup>7</sup> emphasis on thinking about potential policy impacts even before a research project begins underscores his conviction that to affect the lives of large numbers of people, change on this level may be critical and should be a stated aim of participatory research endeavors. In some instances, however, community participants' desires for action may be limited to securing small, individual-level changes.<sup>47</sup> For the outside researcher, an ethical dilemma may therefore involve the tension between respecting community wishes and pushing for the higher-level social change that some consider a defining feature of CBPR.<sup>13</sup>

Such a dilemma emerged in the course of the Language of Light project, a photovoice project that included three outside cofacilitators and a diverse group of homeless shelter residents in Ann Arbor, Michigan.<sup>47</sup> Consistent with Kelly's<sup>7,8</sup> ecological principles, an emphasis was placed on identifying and building on human resources and on high-level

community involvement, with the shelter residents taking part in three 4-hour workshops in which they discussed issues of picture taking, ethics, and power in relation to the new skill they were developing and participated in guided photo shoots. The photovoice method, in which participants are trained in taking pictures to capture their reality and then use the images to dialogue with each other about common themes and look for root causes, ideally also includes the sharing of photos with policy makers and others as a means of affecting broader level change. Although the homeless participants in the Language of Light project were eager to share their photos, however, and proud of the fact that several hundred people, including policy makers, attended the showing of their photos at a local theater, they were not interested in using this or other venues to press for policy-level change, even in the face of a looming new threat to their shelter location.<sup>47</sup> Rather, and while the potential benefits of their growing sense of political efficacy<sup>55</sup> was noted by the outside partners, the participants' priorities continued to rest with individual-level quality-of-life issues. In this situation, rather than pushing for a more ambitious, policy-focused change agenda, the outside researchers played an important role by stepping back to honor the community's desires to pursue far more limited change objectives. Kelly<sup>7</sup> and Israel et al.'s<sup>3</sup> reminder of CBPR's commitment to individual as well as community capacity building indeed reinforces the need for not discounting the importance of microlevel change outcomes in this process.

Numerous other ethical issues may arise in the action phase of CBPR, among them risks to community participants and to outsider researchers, particularly when they tackle topics that involve crossing powerful entrenched interests.<sup>51</sup> Echoing Kelly's<sup>30</sup> early admonition, Farquhar and Wing<sup>51</sup> (p. 238) point out that "no research question, method or result can be separated from its social context," and as a consequence, both outside researchers and community participants must be prepared for the sometimes difficult consequences that this may entail. Developing early on a team or subgroup of outside researchers and community members to study and monitor potential side effects of research participation is one means advocated by Kelly<sup>8</sup> for exploring and attending to such unplanned consequences. Whatever specific method is chosen, however, working with participants to track both positive and negative outcomes of participation in the research and working collaboratively to avoid or ameliorate adverse effects constitute key components of an ecological and ethically sound approach to CBPR.

## CONCLUSION

CBPR frequently involves thorny ethical challenges for outside researchers and their community partners. Yet despite such challenges and obstacles, CBPR provides an approach to research that shows increasing promise as we attempt to address many of today's most intractable health and social problems.<sup>6</sup> By involving and building on the strengths of multiple stakeholders in the research process, CBPR offers the opportunity to achieve what physician Roz Lasker and her colleagues at the New York Academy of Medicine<sup>56</sup> term "partnership synergy," tackling difficult issues more effectively than any one partner could do alone.

Outside researchers interested in engaging with communities in CBPR should facilitate continued dialogue among all partners concerning the many ethical challenges that arise in such work. Memorandums of understanding and the early setting of formal or informal ground rules are among the mechanisms that usefully may be employed to help prevent or successfully resolve difficult issues as they arise. Workshops in which commu-

nity and academic partners share their views of what constitutes meaningful and “valid” research also may be helpful in fostering dialogue and colearning.

Finally, CBPR partners may benefit from using the detailed set of guidelines and criteria developed by Green and his colleagues<sup>11</sup> at the University of British Columbia for assessing the goodness of fit between CBPR projects and the principles of participatory research ([www.ihpr.ubc.ca/guidelines.html](http://www.ihpr.ubc.ca/guidelines.html)). The 24 guidelines are grouped under six headings: participants and the nature of their involvement, origin of the research question, purpose of the research, process and context—methodological implications, opportunities to address the issue of interest, and nature of the research outcomes. A range of scaled question items is included under each heading, among them are the following.

- Did the impetus for the research come from the community?
- Is attention given to barriers to participation, with consideration of those who have been underrepresented in the past?
- Can the research facilitate collaboration between community participants and resources external to the community?
- Do community participants benefit from the research outcomes?
- Is there attention to, or an explicit agreement between, researchers and community participants with respect to ownership and dissemination of the research findings?

Using these and related questions as the basis of dialogue may help outside researchers and their community partners navigate the difficult terrain of CBPR while attempting to address some of the ethical issues that often are inherent in this challenging but highly promising approach to community-based research and practice.

## References

1. Green LW, Mercer SL: Can public health researchers and agencies reconcile the push from funding bodies and the pull from communities? *Am J Public Health* 91(12):1926-1929, 2001.
2. Goodman R: Community-based participatory research: Questions and challenges to an essential approach. *J Public Health Manag Practice* 7(5):v-vi, 2001.
3. Israel BA, Schulz AJ, Parker EA, Becker AB: Review of community-based research: Assessing partnership approaches to improve public health. *Annu Rev Public Health* 19:173-202, 1998.
4. Beauchamp D: Public health as social justice. *Inquiry* 12:2-14, 1976.
5. Cornwall A, Jewkes R: What is participatory research? *Soc Sci Med* 41(12):1667-1676, 1995.
6. Minkler M, Wallerstein N: Introduction to Community-Based Participatory Research, in Minkler M, Wallerstein N (eds.): *Community-Based Participatory Research*. San Francisco, Jossey-Bass, 2003, pp. 3-26.
7. Kelly JG, Dassoff N, Levin I, Schreckengost J, Stelzner SP, Altman E: A guide to conducting prevention research in the community: First steps. *Prev Human Services* 6(1):1-174, 1988.
8. Kelly JG: Seven criteria when conducting community-based prevention research: A research agenda and commentary, in Steinberg JA, Silverman MM (eds.): *Preventing Mental Disorders: A Research Perspective*. Rockville, MD, National Institute of Mental Health, 1987, pp. 57-72.
9. Kelly JG, Mock LO, Tandon DS: Collaborative inquiry with African-American community leaders: Comments on a participatory action research process, in Reason P, Bradbury H (eds.): *Handbook of Action Research*. London, Sage, 2001, pp. 348-355.
10. Jones CP: Levels of racism: A theoretical framework and a gardner's tale. *Am J Public Health* 8:1212-1215, 2000.
11. Green LW, George MA, Daniel M, et al: *Study of Participatory Research in Health Promotion*. Ottawa, Royal Society of Canada, 1995.

12. Wallerstein N: Power between evaluator and community: Research relationships within New Mexico's healthier communities. *Soc Sci Med* 49:39-53, 1999.
13. Hall BL: From margins to center: The development and purpose of participatory action research. *Am Sociologist* 23:15-28, 1992.
14. Zimmerman MA: Empowerment theory: Psychological, organizational and community levels of analysis, in Rappaport J, Seidman E (eds.): *Handbook of Community Psychology*. New York, Plenum, 2000, pp. 43-63.
15. *The Community Health Scholars Program: Stories of Impact*. Ann Arbor, University of Michigan, Community Health Scholars Program, 2002.
16. Ansley F, Gaventa J: Researching for democracy and democratizing research. *Change*, January-February, 1997, pp. 46-53.
17. Lewin K: Action research and minority problems. *J Soc Issues* 2:34-46, 1946.
18. Brown LD, Tandon R: Ideology and political economy in inquiry: Action research and participatory research. *J Appl Behav Sci* 19(3):277-294, 1983.
19. Fals-Borda O: The application of participatory action-research in Latin America. *Int Sociol* 2:329-347, 1987.
20. Freire P: Creating alternative research methods: Learning to do it by doing it, in Hall B, Gillette A, Tandon R (eds.): *Creating Knowledge: A Monopoly? Participatory Research in Development*. New Delhi, Society for Participatory Research in Asia, 1982, pp. 29-37.
21. Freire P: *Pedagogy of the Oppressed*. New York, Seabury, 1970.
22. Maguire P: *Doing Participatory Research: A Feminist Approach*. Amherst, MA, Center for International Education, 1987.
23. Duran E, Duran B: *Native American Postcolonial Psychology*. Albany, State University of New York Press, 1995.
24. Fine M: Working the hyphens, in Denzin NK, Lincoln YS (eds.): *Handbook of Qualitative Research*. Thousand Oaks, CA, Sage, 1994, pp. 70-82.
25. Gebbie K, Rosenstock L, Hernandez LM: *Who Will Keep the Public Healthy? Educating Public Health Professionals for the 21st Century*. Washington, DC, Institute of Medicine, 2002.
26. Viswanathan M, Ammerman A, Eng E, Gartlehner G, Lohr KN, Rhodes S, Sammuell-Hodge C, Maty S, Lux L, Webb L, Sutton SF, Swinson T, Jackman A, Whitener L: *Community-Based Participatory Research, Evidence Report*. Rockville, MD, Agency for Healthcare Research and Quality, in press.
27. Aaron KF, O'Toole TP (eds.): Community-Based Participatory Research (Special issue). *J Gen Intern Med* 18(110):139-334, 2003.
28. Maurana C, Wolff M, Beck BJ, Simpson DE: *Working with our communities: Moving from service to scholarship in the health professions*. San Francisco, Community-Campus Partnerships for Health, 2000.
29. Seifer SD: Documenting and assessing community-based scholarship: Resources for faculty, in Minkler M, Wallerstein N (eds.): *Community-Based Participatory Research for Health*. San Francisco, Jossey-Bass, 2003, pp. 429-435.
30. Kelly JG: Ecological constraints on mental health services. *Am Psychol* 21:535-539, 1966.
31. Chavez V, Duran B, Baker QE, Avila MM, Wallerstein N: The dance of race and privilege in community-based participatory research, in Minkler M, Wallerstein N (eds.): *Community-Based Participatory Research for Health*. San Francisco, Jossey-Bass, 2003.
32. Duran B, Duran E, Brave Heart MYH: Native Americans and the trauma of history, in Thornton R (ed.): *Studying Native America: Problems and Prospects in Native American Studies*. Madison, University of Wisconsin Press, 1998, pp. 60-78.
33. Brave Heart MYH, De Bruyn LM: The American Indian holocaust: Healing historically unresolved grief. *Am Indian Alsk Native Ment Health Res* 2:60-82, 1998.
34. Tervalon M, Murray-Garcia J: Cultural humility vs. cultural competence: A critical distinction in defining physician training outcomes in medical education. *J Health Care Poor Underserved* 9(2):117-125, 1998.
35. Stoecker R: Are academics irrelevant? *Am Behav Sci* 42(5):840-854, 1999.



36. Reason P: *Participation in human inquiry*. London, Sage, 1994.
37. Roe KM, Minkler M, Saunders FF: Combining research, advocacy and education: The methods of the Grandparent Caregiving Study. *Health Educ Q* 22(4):458-475, 1995.
38. Labonté R: Community empowerment: The need for political analysis. *Can J Public Health* 80(2):87-88, 1989.
39. Minkler M, Fadem P, Perry M, Blum K, Moore L, Rogers J: Ethical dilemmas in participatory action research: A case study from the disability community. *Health Educ Behav* 29(1):14-29, 2002.
40. Nyden PW, Wiewel W: Collaborative research: Harnessing the tensions between researcher and practitioner. *Am Sociol* 24:43-55, 1992.
41. Maltrud K, Polacsek M, Wallerstein N: *Participatory Evaluation Work Book for Community Initiatives*. Albuquerque, University of New Mexico, 1997.
42. Alvarez AR, Gutierrez LM: Choosing to do participatory research: An example and issues of fit to consider. *J Community Practice* 9(1):1-20, 2001.
43. Sullivan M, Chao SS, Allen CA, Kone A, Pierre-Louis M, Krieger J: Community-researcher partnerships: Perspectives from the field, in Minkler M, Wallerstein N (eds.): *Community-based participatory research for health*. San Francisco, Jossey-Bass, 2003, pp. 113-130.
44. El-Askari G, Freestone J, Irizarry C, et al: The Healthy Neighborhoods Project: A local health department's role in catalyzing community development. *Health Educ Behav* 25(2):146-159, 1998.
45. Themba MN: *Making Policy, Making Change: How Communities Are Taking Law Into Their Own Hands*. Berkeley, CA, Chardon, 1999.
46. Yoshihama M, Carr ES: Community participation reconsidered: Feminist participatory action research with Hmong women. *J Community Practice* 10(4):85-103, 2002.
47. Wang CC, Cash JL, Powers LS: Who knows the streets as well as the homeless? Promoting personal and community action through photovoice. *Health Promotion Practice* 1:81-89, 2000.
48. Ong A: *The Ethnography of Resistance*. Berkeley, University of California Press, 1991.
49. Wallerstein N, Duran B: The conceptual, historical, and practice roots of community-based participatory research and related participatory traditions, in Minkler M, Wallerstein N (eds.): *Community-Based Participatory Research for Health*. San Francisco, Jossey-Bass, 2003, pp. 27-52.
50. Reason P, Bradbury H (eds.): *The Handbook of Action Research: Participative Inquiry and Practice*. London, Sage, 2001.
51. Farquhar S, Wing S: Methodological and ethical considerations in community-driven environmental justice research, in Minkler M, Wallerstein N (eds.): *Community-Based Participatory Research for Health*. San Francisco, Jossey-Bass, 2003, pp. 221-241.
52. Brown L, Vega WA: A protocol for community-based research. *Am J Prev Med* 12(4):4-5, 1996.
53. Fawcett SB, Francisco VT, Paine-Andrews A, Schultz JA: A proposal. *Public Health Rep* 115:174-179, 2000.
54. Lee P, Krause N, Goetchius C: Participatory action research with hotel room cleaners: From collaborative study to the bargaining table, in Minkler M, Wallerstein N (eds.): *Community-Based Participatory Research for Health*. San Francisco, Jossey-Bass, 2003, 390-404.
55. Zimmerman MA: The relationship between political efficacy and citizen participation: Construct validation studies. *J Personality Assessment* 53:554-566, 1989.
56. Lasker RD, Weiss ES, Miller R: Partnership synergy: A practical framework for studying and strengthening the collaborative advantage. *Milbank Q* 79(2):179-205, III-IV, 2001.