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Ethics and Community-Based Participatory Research: Perspectives From the Field

Elena M. Bastida, PhD,
Professor and Associate Dean for Research in the School of Public Health at the University of North Texas Health Science Center in Fort Worth, Texas

Tung-Sung Tseng, DrPH, MS, CHES,
Assistant Professor of Behavioral and Community Health Sciences in the School of Public Health at the Louisiana State University Health Sciences Center in New Orleans, Louisiana

Corliss McKeever, MSW, and
President and Chief Executive Officer of the African-American Health Coalition Inc. and Assistant Professor at the Oregon Health and Science School of Nursing Research in Portland, Oregon

Leonard Jack Jr., PhD, MSc, CHES
Associate Dean for Research and Endowed Chair of Minority Health Disparities in the College of Pharmacy at Xavier University in New Orleans, Louisiana

Abstract

Exploring the importance of ethical issues in the conduct of community-based participatory research (CBPR) continues to be an important topic for researchers and practitioners. This article uses the Beyond Sabor Project, a CBPR project implemented in the Lower Rio Grande Valley, as a case example to discuss ethical issues such as the importance of increasing community involvement in research, ensuring that communities benefit from the research, sharing leadership roles, and sensitive issues regarding data collection and sharing. Thereafter, this article concludes with a brief discussion of six principles that can inform the practice of ethical conduct when implementing CBPR studies. This article also lists additional reading resources on the importance of ethics in the conduct of CBPR.

Keywords

community-based cipatory research; health education ethics; professional preparation

Ethical issues in health promotion and education have garnered increasing attention as an important topic in academic research and professional practice. This is especially applicable for community-based participatory research (CBPR), a specific research approach that encourages equity and shared decision making between researchers and community members. The increased use of CBPR warrants the introduction of professional preparation in ethics at the undergraduate and graduate levels in health education and other professions, particularly regarding knowledge, awareness, and skills building. The engagement of individuals from communities of color in research projects is an especially complex and multilayered process that requires increasing attention to ethical practices more than ever. The continuing and widening gap in health disparities along with a myriad of other

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Please address correspondence to Elena Bastida, PhD, MS, University of North Texas Health Center, School of Public Health, 3500 Campus Bowie Blvd., Fort Worth, TX 76107-2699; bastida@hsc.unt.edu.

sociopolitical factors help emphasize the importance of developing a sound ethical approach when undertaking a CBPR study.

It is well established that minority participation in clinical trials, epidemiologic research, and intervention studies have lagged behind that of the majority population (Katz et al., 2008a; Katz et al., 2008b; Powell, Fleming, Walker-McGill, & Lenoir, 2008). This lack of participation is partly explained by the level of suspicion and mistrust found among minority communities regarding their participation in clinical, medical, or behavioral research (Katz et al., 2008a; Katz et al., 2008b). Whether the mistrust is based on actual empirical data, such as the Tuskegee Experiment (Katz et al., 2008a; McCallum, Arekere, Green, Katz, & Rivers, 2006), or the impressions resulting from “parachute” research when community members feel that their participation only serves the purpose of advancing the researcher’s career (Fouad et al., 2001; Robinson & Trochim, 2007), these concerns need to be recognized and addressed within the health promotion and education profession.

Beyond issues of suspicion and mistrust, other critical issues with ethical implications arise when conducting CBPR studies; for example, increasing community involvement in research, ensuring communities benefit from the research, sharing leadership roles and data collection, maintaining mutually beneficial challenges, and sustaining program activities (Asian and Pacific Islander American Health Forum, 2008; Green, 2004; Lincoln, 2001). Addressing these issues becomes even more complex when researchers hold dual roles as community members (e.g., community leader) and academic researchers. When fulfilling these dual roles, academic researchers often do not participate in discussions and training pertaining to ethical principles. In this instance, academic researchers serving in dual roles do not receive training regarding assurances of confidentiality and anonymity that is usually part of the package that other team members receive (Edwards, Lund, & Gibson, 2008). In addition to the resulting strain, researchers may confront a moral or spiritual dilemma. Besides the strain resulting from this dualistic role-playing, researchers may be placed in an uncomfortable position when realizing that one or more partners may not be fully participating in the process.

Avoiding any issue that may damage the researchers’ credibility, ruin trust, and/or give the appearance of favoritism is critically important. It is also critically important that researchers must act ethically because they are obliged to follow codes of conduct that would protect communities from misuse, harm, and abuse. The first step in achieving these goals is to include all partners in the development of a gold-standard CBPR process for each project usually accomplished through an initial orientation covering all the major tenets of the CBPR process. Part of this orientation process would include open discussions between all prospective participants concerning the following topics: roles and responsibilities, compensation, timelines, publications, data ownership, and opportunities for future projects. An excellent example of similar challenges to those noted above were those confronted by Beyond Sabor researchers when first approaching their priority community with the goal of conducting a CBPR study. In meeting these challenges during the initial stages of implementation, the Beyond Sabor team responded by developing its own practical gold-standard approach that became instrumental in gradually mitigating community mistrust.

BEYOND SABOR PROJECT: A CASE EXAMPLE

As already noted, a productive alternative in lessening some of the problems likely to emerge when planning or conducting a CBPR study is to train researchers to respectfully negotiate with communities at the onset of the relationship and to provide full disclosure upfront. As the Beyond Sabor academic team learned, this disclosure is not a one-step process but rather one that requires a continuous discussion among all parties concerned. In the context of expanding the current discussion on ethics, we will examine the general methods of CBPR in the specific situation of the Beyond Sabor study. The lessons learned from this study are particularly applicable to this discussion because the Beyond Sabor study had to directly confront the negative consequences of earlier parachute research studies in the targeted community.

The location of the Beyond Sabor study in the Lower Rio Grande Valley deep in South Texas suitably fits the pattern for parachute studies, because it is the most economically disadvantaged area of the state and 3 of its counties rank among the top 10 most disadvantaged in the United States. Researchers from outside this region find it advantageous to focus on this population when applying for competitive funding in health disparities research. Some principal investigators often remain unaccountable to community residents because their offices are located hundreds of miles away and thus they must rely on local residents as temporary workers for conducting the day-to day activities of the project. These temporary workers are terminated once the data are collected, leaving community residents with very little information on the course of the study or learning about study outcomes. Within this context, the Beyond Sabor researchers were challenged to devise ethical strategies that allowed transparency and accountability in the development of the Sabor intervention. In close collaboration with community advocates and community residents, a code of ethics was developed that became central to the ongoing trust and collaboration that the Beyond Sabor team has built with the community throughout the past 5 years. Following the canons of CBPR, the Beyond Sabor study established a 12-member Advisory Council that consists of community advocates, staff members of community agencies, and community residents; altogether, the Advisory Council includes three local agency directors, two ministers, a community nurse, two practicing physicians, and four unaffiliated community residents. The principal investigator and the project coordinator serve as ad hoc members.

During the initial funding of the first phase of the pilot intervention, the investigators began to consider the importance of developing a code of ethics to help guide the project. Investigators and staff were conscious that to achieve ethical standards in all the various phases of the project, all parties involved with the study had to participate in training sessions that included brainstorming discussions of what ethics meant in the field. Finally, this process came to fruition after the completion of the pilot stage and initiation of the formal implementation of the second phase of the study. Resulting from these deliberations, an ethics code was developed that centered on the following six principles.

Principle 1: Respect

Throughout a 6-month period, a strict code regarding respect in the field was developed with the collaboration of researchers, community advocates, and residents. The academic team was further trained in respecting and legitimating the voice of community participants. Particular attention was given to the training of students on extending respect and full attention to participants' comments. Throughout, the academic team was instructed to build on comments made by study participants and community advocates and never to contradict community participants.

Special training sessions on conflict avoidance and management became part of the research teams' preparation strategies. Also stressed were discussions on keeping all personal matters and possible biases separate from the task at hand. Students were specifically instructed to remain neutral in all participant exchanges not related to the content of the intervention.

Principle 2: Fiduciary Transparency

Because the particular CBPR model on which Beyond Sabor is based calls for community partners as recipients of study funds, every effort was made to share the study's proposed budget with all involved parties. At all times, the research team endeavored to maintain a high level of transparency.

Principle 3: Fairness

Building a strong sense of fairness among all stakeholders is always a top priority when conducting CBPR and it continues to be an essential component of the Beyond Sabor study. All team members are trained to carefully explain the project's inclusion and exclusion criteria. Emphasis is given to the importance of acknowledging principles of fairness when working with minority populations who have not been the recipients of fairness in our society. Fairness is critical to building trust among all involved with the project.

Principle 4: Informed Consent: Always Voluntary

Research projects that focus on populations with limited use of English and those working with populations that experience literacy and numeracy problems, or both, need to make a very special effort to explain the consent form in a simple yet personal style. In the Beyond Sabor study, researchers bring at least five bilingual staff members and students to respond to any questions a future participant may have, while the project coordinator shows the slides. In general, when addressing literacy and numeracy problems, researchers are encouraged to prepare slides that are short and simple; sometimes Beyond Sabor staff members will use a picture to convey an idea. In general, staff members must repeatedly emphasize participants' rights, that their participation in the study is voluntary, and that they have the right to refuse to participate at any time.

Principle 5: Reciprocity

When conducting CBPR studies, researchers need to emphasize the principle of reciprocity. An inclusive approach that conceives and codelivers the project in terms of shared goals, dedication, and responsibility is always recommended. All parties must fully understand their commitment and anticipated contribution to the project. All constituents give and receive from the project; therefore, all interactions are considered reciprocal. In this manner, participants' time and efforts must be carefully acknowledged as being especially valuable. This means acknowledging their contribution in terms of travel time and other related expenses.

Principle 6: Equal Voice and Disclosure

The Beyond Sabor staff has always recognized the importance of running all meetings on the basis of equal voice and full disclosures. Based on this study's experience, all meeting participants should be accorded the same time and acknowledgement, regardless of their role in the project. All ideas should be entertained, and researchers should disclose their own academic interests. In conducting Beyond Sabor, the research team quickly learned that they had to take leadership in moving the study forward and adhering to the scientific principles that guided the study. Promptly reporting laboratory results and other important findings to participants is critical. Study findings should be presented and shared with the community in ways that are understandable and respectful.

No one set of CBPR principles will help researchers avoid all potential problems in this realm. However, keeping the previously mentioned six principles in mind will help build trusting relationships between researchers and prospective study participants that may develop into meaningful and sustainable partnerships. The aim of this article is to provide a brief review of the importance of ethics in CBPR. Shive and Marks (2006) note that "as the health education profession advances training in cultural competency for health promotion, some deliberation may be given to enhancing ethical competency to ensure that adequate examination of the ethical implications of health education methods and outcomes be considered in the context of this diversity" (p. 287). The importance of integrating ethics into CBPR has gained increasing attention over the past several years. Table 1 identifies several publications that offer information that can assist with professional preparation and continuing education in health education regarding ethical dilemmas in CBPR. Notably, ethical issues in CBPR need to be recognized and addressed carefully. In this article, we point out ethical implications in CBPR, such as the increasing need for community involvement in research, ensuring that communities benefit from the research, ameliorating shared leadership roles, and ethically collecting and sharing data. We also described our experience with ethical implications in CBPR as illustrated by a case study. The lesson learned from the Beyond Sabor study is that a strong ethics code is essential for success in CBPR.

In summary, the great success of ethical competency with regard to the six previously discussed principles is based on adherence by researchers and their research team to the highest ethical code of conduct from the beginning to the end. This should be done not only to avoid any potential adverse impact on the researcher's credibility, the validity of the intervention, and reputation of the representative research institution but also to avoid ruining the trust and opportunity for mutually desired relationships with vulnerable populations and communities. Addressing these topics early on in the research process will greatly reduce the potential for less-than-optimal outcomes and help to build trusting relationships that may develop into meaningful, sustainable partnerships (Hartwig, Calleson, & Williams, 2006).

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TABLE 1

A List of Useful Resources for Ethics in Community-Based Participatory Research

1	Kennedy, C., Vogel, A., Goldberg-Freeman, C., Kass, N., & Farfel, M. (2009). Faculty perspectives on community-based research: "I see this still as a journey." *Journal of Empirical Research on Human Research Ethics, 4*(2), 3–16.
2	Horowitz, C. R., Robinson, M., & Seifer, S. (2009). Community-based participatory research from the margin to the mainstream: Are researchers prepared? *Circulation, 119*, 2633–2642.
3	F licker, S., Travers, R., Guta, A., McDonald, S., & Meagher, A. (2007). Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Urban Health, 84*, 478–493.
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