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Ethical Community-Engaged Research: A Literature Review

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Abstract

Health research has relied on ethical principles, such as those of the Belmont Report, to protect the rights and well-being of research participants.

Community-based participatory research (CBPR), however, must also consider the rights and wellbeing of communities. This requires additional ethical considerations that have been extensively discussed but not synthesized in the CBPR literature.

We conducted a comprehensive thematic literature review and summarized empirically grounded discussions of ethics in CBPR, with a focus on the value of the Belmont principles in CBPR, additional essential components of ethical CBPR, the ethical challenges CBPR practitioners face, and strategies to ensure that CBPR meets ethical standards. Our study provides a foundation for developing a working definition and a conceptual model of ethical CBPR.

Ethics, defined as “Norms for conduct that distinguish between acceptable and unacceptable behavior,” play a vital role in research.¹ Clinical and health services researchers rely on ethical principles and practices to ensure that they treat research participants fairly and balance research risks and benefits. Research misconduct, such as abuse of human participants in biomedical experiments, led to the development of ethical standards that guide the oversight of research protocols. The Belmont Report,³ which established the gold standard definition of biomedical research ethics, delineated 3 ethical principles to protect the rights and well-being of individual research participants. First, individual autonomy—respect for persons purports that “individuals should be treated as autonomous agents”³ and that they should be given sufficient information about the study and should independently decide whether they want to participate.⁴ Second, beneficence and nonmaleficence require researchers to maximize benefits and minimize harm to research participants and ensure individuals’ well-being by demanding that researchers carefully consider the risk–benefit ratio of participation.^{5,6} Finally, justice, or the fairness principle,

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Contributors

L. Mikesell supervised the abstract reviews, collated results, and drafted the introduction and Tables 3 and 4 and their corresponding text. E. Bromley drafted the Discussion and Table 2 and its corresponding text. D. Khodyakov drafted Table 1 and its corresponding text and revised the introduction. All authors oversaw a third of the review of full texts, validated other authors’ analyses, revised their sections, and revised the Discussion section.

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Human Participant Protection

No protocol approval was required because no human participants were involved.

requires that researchers equitably distribute the risks and benefits associated with research across society.^{5,7}

In public health, however, researchers focus on the well-being of communities, which creates new ethical dilemmas.^{8,9} Among the ethical issues commonly debated in public health are whether the infringement of individual liberties may be considered a morally legitimate cost of improving community health and whether evidence-based approaches to care that may be culturally problematic should nonetheless be implemented. The principles and practices of community-based participatory research (CBPR) provide a powerful approach for engaging community members in developing and evaluating strategies for improving health. CBPR promotes trust and shared power and decision-making between researchers and community representatives, 2-way capacity building, and mutually beneficial cocreation and dissemination of study findings.^{10–14}

Indeed, CBPR practitioners have questioned the relevance and comprehensiveness of the Belmont principles when applied to the novel ethical situations they confront, including the desire to protect not only individual research participants but also communities and populations.^{15,16} Some have even proposed reconceptualizing the Belmont principles.¹⁷ These practitioners have initiated a conversation about the ethical principles and practices that should guide CBPR, which highlights the need for greater attention to matching research goals to community needs and preferences and establishing community-based review boards.^{18–20} Others have gone further by describing CBPR as an ethical response to past misconduct and arguing that institutional review boards (IRBs) should incorporate some of the lessons of CBPR into the oversight of traditional biomedical research.^{21,22}

Because CBPR ethics are an important and much-debated topic, a definition of and a framework for ensuring ethical CBPR are needed. As a first step toward these goals, we summarized the growing literature on ethics in CBPR by conducting a comprehensive thematic literature review²³ structured around 4 questions:

- How do CBPR researchers understand the meaning of the Belmont principles in partnered projects?
- What principles that go beyond the ones described in the Belmont Report characterize ethical CBPR?
- What ethical challenges do CBPR practitioners face when conducting research in close collaboration with community partners?
- How can research integrity be ensured in CBPR?

Our review identified commonly used principles of ethical CBPR and may serve as groundwork for developing a comprehensive conceptual model for conducting ethical CBPR.

METHODS

Our comprehensive thematic literature review²³ focused on CBPR in health research. We searched titles, abstracts, and keywords of peer-reviewed articles published between January 1, 1990, and August 8, 2012, and indexed in 4 databases that cover a wide range of health, nursing, behavioral science, and social science publications: PubMed, CINAHL, PsychINFO, and Web of Science. We used a comprehensive list of search terms that describe research ethics (e.g., “ethics,” “research integrity,” “misconduct”) and CBPR (e.g., “community engaged,” “community-engaged,” “community-driven,” “community-initiated,” “partnered,” “participatory,” “action research”).

We imposed 7 inclusion criteria: articles were in English; were published in a peer-reviewed journal; discussed research conducted entirely in the United States, United Kingdom, or Canada; had a health focus; described research conducted in close collaboration with underprivileged or underserved community partners; provided specific examples from direct research experience; and focused primarily or mostly on research ethics. The initial search returned 977 titles; we were unable to locate 7. We screened the remaining 970 abstracts and selected 210 articles as potentially eligible for inclusion. We reviewed the full text of these 210 articles and excluded 153, which yielded a final sample of 57 articles for our review.^{4-7,15,16,18-22,24-69}

We used conventional content analysis⁷⁰ to identify articles relevant to our guiding questions and provide empirically grounded examples of the meaning of the Belmont principles in CBPR, as well as components of, challenges to, and principles of ensuring ethical CBPR. We first read and summarized a subset of 12 articles (21%); compared our summaries; discussed, reviewed, and reconciled discrepancies; and clarified the defining features of each content category. Then, each of us summarized one third of the included articles; we all reviewed and approved all summaries to ensure reliability.

RESULTS

Of the 57 articles in our review, 38 discuss CBPR projects that took place in the United States, 13 in Canada, and 6 in the United Kingdom. Authors describe CBPR experiences in a variety of settings and populations: tribal, aboriginal, or indigenous communities (n = 15); low socioeconomic status African American, Hispanic, immigrant, or refugee communities (n = 12); at-risk women or youths (n = 8); persons with medical conditions (n = 7); and communities at risk for toxic environmental exposures (n = 3). Twelve articles do not focus on a particular community. Thirty-seven articles address research ethics as the primary focus; the remaining 20 discuss ethics as one of several foci. Appendixes A through D (available as a supplement to the online version of this article at <http://www.ajph.org>) list the articles that address each of our research questions.

The Belmont Principles in CBPR

Our findings suggest that although the principles of autonomy, beneficence, and justice are commonly used to determine whether biomedical research is ethical, their relevance to community-engaged research is an open question. Almost all reviewed articles suggest that an evaluation of ethics in CBPR should focus not only on individual participants but also on the community at large. Thirty-eight articles discuss how the meaning of the Belmont principles changes in community-engaged research and how the interests of individuals and the community could be protected. The principles of community autonomy (n = 30), however, tend to be more frequently discussed than those of community justice (n = 18) and beneficence (n = 17; Table 1).

Thirty articles suggest that research projects are expected not only to respect and protect individual participants' rights, but also to protect community autonomy. By maintaining standards of high-quality research and cultural congruence,¹⁸ community researchers provide a sense of community self-determination and show an appreciation of community needs and interests,⁷ thereby creating a structure that can protect a community and its individual members from harm and exploitation.^{7,24} Moreover, sensitivity to community needs and research requirements helps partnered research projects develop valid and generalizable knowledge that benefits the community and improves research protocols by incorporating community expertise.⁴

Community autonomy in CBPR, however, is a multifaceted concept. Twenty-five articles provide examples in which respect for community needs, interests, values, and strengths illustrates community autonomy. Joint interpretation of findings and dissemination of results to the community are important aspects of community autonomy, according to 7 articles, regardless of the fact that they raise new ethical challenges.^{25–27} Five articles consider either voluntary community participation in research,²⁸ such as conducting research with, rather than on, communities, or recognition of community dignity and worth, expressed by engaging communities in all aspects of research,⁵ as characteristics of community autonomy.

Community justice, which in CBPR is often understood as the process of negotiating compromises between researchers and communities to ensure fairness for both individual study participants and communities engaged in research, is discussed in 18 articles.⁵ Seven articles assert that both the burden of participation and research benefits are expected to be equitably distributed in communities, but that community benefits should be prioritized.²⁹ Although including all relevant community stakeholder groups in research and carefully considering inclusion and exclusion criteria may be a path to fairness,⁷ Flicker and Worthington, for example, suggest that community stakeholders' diversity may create conflicts among them, complicating the process of achieving community justice.⁵⁶

Although the traditional understanding of beneficence and non-maleficence is that research should maximize individual benefits and minimize participant harm, 14 of 17 articles that mention community beneficence suggest that ethical CBPR should also take into account risks and benefits to community researchers and the community at large.^{5,25,31} Glass and Kaufert argue that community members may be harmed by research findings, either because they internalize “negative research results about their community,” or because data collected for one purpose are later used for another purpose without permission.^{4(p34)} Several authors, including Flicker and Guta,³² note that academic research ethics committees do not typically focus on community risk–benefit analyses and rarely ask questions about broader study impact.

Components of Ethical CBPR

Overall, reviewed articles tend to describe high-quality CBPR as an ethical practice. Some authors explicitly view CBPR as a response to historical ethical misconduct and as the only ethical approach to conducting research with minority or underprivileged communities.²¹ In the words of Frazier et al., “collaboration is less an option than an ethical obligation.”^{33(p125)} Others, however, describe CBPR as a way to solve ethical problems³² by ethically engaging vulnerable populations in research.³⁴ Brugge and Missaghian point out that the practice of CBPR is similar to the requirements of a community research review board.³⁵

Indeed, the components that define ethical CBPR (Table 2) are similar to the principles and procedures that define the method of CBPR itself. Community collaboration is described in 54 articles as a critical component of ethical CBPR. Collaboration requires community involvement and true mutuality, such as through engagement,^{26,36} sharing of experience and leadership,^{37,38} development of trust,^{39,40} transparency,⁶ and mutual empowerment.⁴¹ Ethical CBPR requires ongoing dialogue and negotiation with communities.⁴² Some authors clarify that this means that communities will help define what constitutes ethical research. The use of a relational paradigm⁴³ and an emphasis on reciprocity⁴² or reflexive research ethics⁴⁴ are strategies endorsed for collaborative interpretation of ethical issues in CBPR.

The community significance of ethical CBPR is mentioned in 44 articles. Answering a question that is relevant to a community is described as a key component of ethical CBPR in 39 articles; 33 say that CBPR is ethical when the community has initiated the research

question (“ethically responsible population-based studies must seriously consider community needs and priorities”^{30(p241)}. “[G]iving marginalized communities an opportunity to shape research agendas” is described as a feature of ethical CBPR.^{32(p5)}

Thirty-five articles say that ethical CBPR results in various returns for a community on its investment in a project. CBPR is not ethical unless it results in a tangible community benefit,¹⁵ determined through collaboration, according to 22 articles.^{32,45} Authors also note that “benefits other than knowledge are important goals of research,”²⁹ and that both processes and outcomes can lead to community benefits.¹⁸ Nineteen articles describe a return for the community as a byproduct of the social action orientation of this kind of research: CBPR aims to generate knowledge that leads to social change, enhancement of community well-being,⁴⁶ and “knowledge that reveals and challenges systemic problems rather than reinforcing relations of dominance.”^{45(p41)} CBPR also has “emancipatory potential.”^{47(p2336)} Seventeen articles explicitly mention the need for community capacity building in ethical CBPR.²⁰ Sustainability, such as activities and partnerships that continue after project completion, is described as an important community return in 5 articles.^{48,49}

Community control is described as a component of ethical CBPR in 23 articles, with 18 specifying joint ownership of data or negotiation of control of data as particularly relevant. Two authors use the acronym OCAP (ownership, control, access, and possession) to summarize the principle of community control.^{45,50} Nine articles mention the need to focus on community strengths rather than deficits to facilitate community partners’ contributions to the research process.

Challenges of Ethical CBPR

CBPR presents new challenges that many researchers discuss as ethical dilemmas (Table 3). Twenty-four articles discuss insider–outsider tensions in CBPR, 1 of the 5 most commonly discussed ethical challenges we encountered. Tensions arising from differing expectations, assumptions, and agendas of community and academic partners that involve conflicting beliefs about research aims and outcomes are described in 17 articles. For example, some authors caution that academic partners may appear inflexible or insensitive because their priorities might focus on meeting their research needs and requirements rather than on community needs.^{39,49} Others warn that community members’ lack of experience in adhering to research protocols may become a barrier to completing projects.^{19,49,51,52} Similarly, 17 articles regard academic–community power differentials as resulting from cultural differences, ignorance about such dissimilarities, or challenges associated with respecting them. Seeking equality among partners with varying backgrounds and skill sets,^{19,52,53} addressing coercion and racism,²⁷ and overcoming communities’ mistrust are commonly discussed ethical challenges.^{18,46,48}

Although protecting communities is an ethical priority of CBPR, 22 articles consider it a challenge. The complexity of adequately respecting both individuals and the community at large is discussed in 18 articles. Managing informed consent, a commonly discussed method of protecting community autonomy, is also challenging, because obtaining the consent of a community is not straightforward.^{4,21,26,45} Participants are researchers, and managing these dual roles may complicate the process of obtaining informed consent. For example, who should count as human participants and from whom should consent be obtained?^{24,45,47,54,55} Maintaining dual roles also results in questions about how to keep participation and outcome data confidential.^{24,26,45,46,54} For example, Williamson and Prosser consider the ethical obligation to maintain frequent and transparent communication among participants as complicating the effort to maintain anonymity and privacy.⁵⁴

Community representation is presented as a challenge to ethical CBPR in 15 articles, because it is not always clear who should represent or speak for the community. Authors often question who should sit on community advisory boards, approve the research study, and consult throughout the research project.^{4,5,7,21,27,29,30,56} Such problems are especially salient in projects that work with multiple or diverse communities.^{5,36,42,52,57}

Ethical arrangements for data sharing and the interpretation and dissemination of results are described as a negotiation process in 12 articles. Such negotiation is particularly challenging when results are not flattering or beneficial to the community.²² Because benefiting communities is a principle of engaged research, some authors question whether negative findings should be disseminated or published.^{4,5,25–27}

Although 12 articles consider reviews by an independent ethics committee to be crucial for upholding ethical standards of research, authors note that IRBs are ill equipped to address the needs of community-engaged researchers.^{16,49,58–61} Authors suggest that IRBs (1) are concerned with individuals and not with community well-being^{16,49,61}; (2) require that all research procedures be approved before research has begun, even though CBPR is dynamic and often requires continual assessment and ongoing adjustments to research protocols^{58,59} and (3) are unfamiliar with CBPR, which may use nontraditional research procedures and hold different beliefs about features IRBs prioritize in their evaluations (e.g., assumptions about data ownership).^{50,59,60}

Ensuring Ethical CBPR

Table 4 illustrates strategies to ensure ethical CBPR. Articles suggest that effectively engaging communities requires researchers to be aware of community values and expectations.^{4,36,51,59,60} Roughly half of the articles (n = 30) note that the way to ensure ethical CBPR is to adequately uphold the central principles of CBPR. Researchers are urged to actively engage and respect communities by involving community members early in the project^{41,60} and during all its stages, including data interpretation^{6,7,20,30,43,51,62}; seek community approval on all decisions or engage in shared decision-making^{4,6,26,63–65}; establish appropriate and meaningful partnerships with communities^{4,42,64}; hold regular community meetings to encourage “the sharing of cultural knowledge”^{43(p312)}; organize researcher and community training and workshops^{29,31,41,44,48,64}; and recognize community needs and support community interests,^{4,46} even if it means sacrificing the researchers’ own personal interests.^{29,66}

Transparency is favored in 29 articles as a way of conducting ethical CBPR. Authors primarily discuss 2 methods for achieving transparency. Seventeen articles specify the general need for open, honest, and frequent communication, which might include regular meetings attended by all partners⁴⁷ and multiple channels of communication and feedback mechanisms, such as suggestion sheets, community bulletins, and meeting notes.^{42,46,51,52,67} Upfront development of formalized research guidelines and data-sharing protocols that “[outline] the expectations of the researcher, and cover ownership of data, dissemination, and confidentiality”^{46(p56)} is recommended in 17 articles, because it can help prevent feelings of resentment, disappointment, or confusion.^{37,38}

A recommendation that CBPR projects should develop community advisory boards or steering committees appears in 23 articles. These are mechanisms to make contact and build connections with the community,^{32,42} ensure that the project is sensitive to the community and culturally competent,^{30,36,66,68} minimize risks to the community,^{34,40,60} address partner concerns and challenges,²¹ allow projects to seek community advice or approval on research decisions,^{18,19,21,24,36,42,60} enable the development of research protocols,⁴⁸ and help researchers ascertain the needs and wishes of partners and build trust.⁶⁹

Some authors recognize the importance of research oversight: 13 articles recommend additional education for IRBs regarding community-engaged research approaches, and 11 recommend the development of community review boards in addition to IRBs. Four articles say explicitly that ethical monitoring is most fair when overseen by an independent reviewer or review body.^{6,47,49,58} Two articles briefly mention that ethical frames derived from clinical work (e.g., professional ethics) can be used as guides to ensure ethical CBPR.^{32,54}

DISCUSSION

Our literature review substantiates the wide interest in ethics in community-engaged research. We identified 977 articles that discuss ethics in CBPR and 57 that meet our inclusion criteria. Our results support previous studies that show that the Belmont principles do not provide a comprehensive guide to research ethics in CBPR.¹⁷ Although some CBPR practitioners find these principles useful when interpreted for the community rather than the individual, many say that Belmont-defined ethical standards are necessary but not sufficient to protect vulnerable communities from research abuses.³⁴ Although CBPR practitioners do not question the importance of the autonomy and well-being of individual participants,^{28,41,43} they may take issue with the ways these principles are used in traditional research models^{47,48} and call for supplementing them with additional principles.

Authors also largely agree on the additional principles that define ethical CBPR. Nonetheless, the principles involved in conducting ethical CBPR are largely synonymous with the principles of CBPR itself: close collaboration, trust, mutuality, shared power and decision-making, and joint data ownership are typical examples of such principles. Indeed, authors often describe CBPR as a practice with multiple identities and objectives: a research method, an ethical practice, and (for some) a form of social activism. Because the definitions of ethical CBPR are so similar to the definition of CBPR, ensuring the ethics of CBPR often entails doing more and better CBPR. Rarely do authors mention that conducting CBPR does not automatically ensure the ethics of the work.¹⁸

This places ethics in CBPR at a crossroads. Three areas for future work are evident. First, high-quality CBPR is assumed to be ethical, yet reviewed articles describe few measurable objectives or uniform guidelines for ensuring that CBPR is conducted to these high standards. For instance, the most commonly mentioned ways to ensure ethical CBPR—adequately engage communities and foster transparent communication—are CBPR principles and not mechanisms for evaluating their implementation. Moreover, the same CBPR principles (e.g., joint ownership and interpretation of data) are often simultaneously discussed as components of ethical CBPR, challenges to ethical CBPR, and ways of ensuring research integrity.

Although the education of IRB members and the establishment of community IRBs to review research are promising strategies for ensuring CBPR ethics, it remains unclear how outside oversight bodies or participants themselves can verify the extent to which such principles as inclusion, mutuality, community benefit, and community control are being used in CBPR projects and who should be given the responsibility to adjudicate the ethics of community-engaged research. Even if practitioners can resolve the challenges of community representation and insider–outside tensions,²⁹ the principles of CBPR do not provide detailed guidance for ensuring the ethical conduct of CBPR. Thus, there is a need to develop a conceptual framework for ensuring research integrity in CBPR.

Second, although the method of valid scientific research and the principles that determine its ethical conduct are distinct, CBPR is both a scientific method and an ethical practice. Reviewed articles do not clarify when a CBPR project strikes an appropriate balance

between these objectives. As Brugge and Kole say of the participants in a community-engaged project,

The researchers were firm in the opinion that good science is related to research methods, while the other interviewees were just as certain that good science is science that helped the community solve its problems.^{15(p499)}

Some authors argue that academic research goals will need to be viewed as subordinate to the goals of achieving true mutuality and inclusion.²⁹ If this is the case, mechanisms to verify that these ethical principles are achieved are all the more critical.

Third, authors seem to agree that ethics in CBPR are emergent and situation specific. Whereas ethical procedures in traditional research are approved ahead of time, CBPR practitioners view ethics as involving a fluid, negotiable, and iterative process requiring continual reflection.^{17,41} What appears ethical in one community may not be ethical in another⁵⁶; therefore the ethical principles in CBPR can be defined as principles in evolution.⁴⁵ Although it reflects the nature of CBPR, this process orientation exacerbates the challenge of ensuring the ethics of community-partnered work. In light of the considerable time commitment that high-quality CBPR requires, more frequent or ongoing ethical oversight may seem onerous. Nonetheless, the ethical implications of various study choices may need to be reviewed by research and community participants in a transparent process throughout the course of a project. Moreover, timely and efficient ethics review by committees that consist of both academic and community partners may be needed to provide objective oversight when ethical challenges arise.⁵⁹

Limitations

We used broad search terms, which identified a large number of articles of variable quality, many of which did not exclusively focus on ethics. Although our inclusion– exclusion criteria helped us identify relevant, empirically grounded articles, some theoretical articles were undoubtedly excluded from our final data set.

Our set of articles demonstrated significant variability in nature, scope, purpose, and quality. At the same time, the diversity of included articles helped us learn about CBPR ethics in different settings, ranging from environmental health to genetics. In addition, taking a comprehensive thematic approach to the literature review, which is appropriate for reviewing descriptive and qualitative research,⁷¹ helped reveal and illustrate the intricate nature of ethics in CBPR.

Conclusions

To our knowledge, our study was the first comprehensive thematic literature review on ethics in CBPR. Our results show the importance of this topic and suggest that one of CBPR's most notable strengths—the dynamic and reflexive nature of its ethics—opens important new venues for future research. Moreover, these results provide a needed foundation for developing a working definition and a conceptual model of ethical CBPR.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Resnik, DB. [Accessed August 29, 2013] What is ethics in research and why is it important? National Institute of Environmental Health Sciences. 2011. Available at: <http://www.niehs.nih.gov/research/resources/bioethics/whatis>.
2. Emanuel EJ, Wendler D, Grady C. What makes clinical research ethical? *JAMA*. 2000; 283(20): 2701–2711. [PubMed: 10819955]
3. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects Research*. Washington, DC: US Department of Health, Education, and Welfare; 1979.
4. Glass KC, Kaufert J. Research ethics review and aboriginal community values: can the two be reconciled? *J Empir Res Hum Res Ethics*. 2007; 2(2):25–40. [PubMed: 19385793]
5. Gilbert SG. Supplementing the traditional institutional review board with an environmental health and community review board. *Environ Health Perspect*. 2006; 114(10):1626–1629. [PubMed: 17035155]
6. Santos L. Genetic research in native communities. *Prog Community Health Partnersh*. 2008; 2(4): 321–327. [PubMed: 20208312]
7. Story L, Hinton A, Wyatt SB. The role of community health advisors in community-based participatory research. *Nurs Ethics*. 2010; 17(1):117–126. [PubMed: 20089631]
8. Kass NE. An ethics framework for public health. *Am J Public Health*. 2001; 91(11):1776–1782. [PubMed: 11684600]
9. Quandt SA, Arcury TA, Pell AI. Something for everyone? A community and academic partnership to address farmwork pesticide exposure in North Carolina. *Environ Health Perspect*. 2001; 109(suppl 3):435–441. [PubMed: 11427393]
10. Castleden H, Morgan VS, Lamb C. “I spent the first year drinking tea”: exploring Canadian university researchers’ perspectives on community-based participatory research involving indigenous peoples. *Can Geogr*. 2012; 56(2):160–179.
11. Arcury TA, Austin CK, Quandt SA, Saavedra R. Enhancing community participation in intervention research: farmworkers and agricultural chemicals in North Carolina. *Health Educ Behav*. 1999; 26(4):563–578. [PubMed: 10435238]
12. Israel BA, Coombe CM, Cheezum RR, et al. Community-based participatory research: a capacity-building approach for policy advocacy aimed at eliminating health disparities. *Am J Public Health*. 2010; 100(11):2094–2102. [PubMed: 20864728]
13. Rao P, Arcury TA, Quandt SA. Student participation in community-based participatory research to improve migrant and seasonal farmworker environmental health: issues for success. *J Environ Educ*. 2004; 35(2):3–15.
14. Strong LL, Israel BA, Schulz AJ, et al. Piloting interventions within a community-based participatory research framework: lessons learned from the Health Environments Partnership. *Progress in Community Health Partnerships*. 2009; 3(4):327–334. [PubMed: 20097994]
15. Brugge D, Kole A. A case study of community-based participatory research ethics: the Healthy Public Housing Initiative. *Sci Eng Ethics*. 2003; 9(4):485–501. [PubMed: 14652901]
16. Shore N, Brazauskas R, Drew E, et al. Understanding community-based processes for research ethics review: a national study. *Am J Public Health*. 2011; 101(suppl 1):S359–S364. [PubMed: 21164086]
17. Shore N. Re-conceptualizing the Belmont Report. *J Community Pract*. 2007; 14(4):5–26.
18. Blumenthal DS. A community coalition board creates a set of values for community-based research. *Prev Chronic Dis*. 2006; 3(1):A16. [PubMed: 16356369]
19. 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*. 2002; 29(1):14–29. [PubMed: 11822550]
20. Brown P, Morello-Frosch R, Brody JG, et al. Institutional review board challenges related to community-based participatory research on human exposure to environmental toxins: a case study. *Environ Health*. 2010; 9:39. [PubMed: 20637068]

21. Buchanan DR, Miller FG, Wallerstein N. Ethical issues in community-based participatory research: balancing rigorous research with community participation in community intervention studies. *Prog Community Health Partnersh.* 2007; 1(2):153–160. [PubMed: 20208234]
22. Flicker S, Travers R, Guta A, McDonald S, Meagher A. Ethical dilemmas in community-based participatory research: recommendations for institutional review boards. *J Urban Health.* 2007; 84(4):478–493. [PubMed: 17436114]
23. Jesson, J. *Doing Your Literature Review: Traditional and Systematic Techniques.* London, UK: Sage; 2011.
24. Whittle J, Fletcher KE, Morzinski J, et al. Ethical challenges in a randomized controlled trial of peer education among veterans service organizations. *J Empir Res Hum Res Ethics.* 2010; 5(4): 43–51. [PubMed: 21133786]
25. Wing S. Social responsibility and research ethics in community-driven studies of industrialized hog production. *Environ Health Perspect.* 2002; 110(5):437–444. [PubMed: 12003746]
26. Holkup PA, Tripp-Reimer T, Salois EM, Weinert C. Community-based participatory research: an approach to intervention research with a Native American community. *ANS Adv Nurs Sci.* 2004; 27(3):162–175. [PubMed: 15455579]
27. Minkler M. Ethical challenges for the “outside” researcher in community-based participatory research. *Health Educ Behav.* 2004; 31(6):684–697. [PubMed: 15539542]
28. Wright DN, Hopkinson JB, Corner JL, Foster CL. How to involve cancer patients at the end of life as co-researchers. *Palliat Med.* 2006; 20(8):821–827. [PubMed: 17148537]
29. Chen DT, Jones L, Gelberg L. Ethics of clinical research within a community-academic partnered participatory framework. *Ethn Dis.* 2006; 16(1, suppl 1):S118–S135. [PubMed: 16681135]
30. Marshall PA, Rotimi C. Ethical challenges in community-based research. *Am J Med Sci.* 2001; 322(5):241–245. [PubMed: 11721794]
31. Hyatt RR, Gute DM, Pirie A, Page H, Vasquez I, Dalembert F. Transferring knowledge about human subjects protections and the role of institutional review boards in a community-based participatory research project. *Am J Public Health.* 2009; 99(suppl 3):S526–S531. [PubMed: 19890152]
32. Flicker S, Guta A. Ethical approaches to adolescent participation in sexual health research. *J Adolesc Health.* 2008; 42(1):3–10. [PubMed: 18155024]
33. Frazier SL, Formoso D, Birman D, Atkins MS. Closing the research to practice gap: redefining feasibility. *Clin Psychol Sci Pract.* 2008; 15(2):125–129.
34. Ellis BH, Kia-Keating M, Yusuf SA, Lincoln A, Nur A. Ethical research in refugee communities and the use of community participatory methods. *Transcult Psychiatry.* 2007; 44(3):459–481. [PubMed: 17938156]
35. Brugge D, Missaghian M. Protecting the Navajo People through tribal regulation of research. *Sci Eng Ethics.* 2006; 12(3):491–507. [PubMed: 16909151]
36. Foster MW, Bernsten D, Carter TH. A model agreement for genetic research in socially identifiable populations. *Am J Hum Genet.* 1998; 63(3):696–702. [PubMed: 9718343]
37. Macaulay AC, Cross EJ, Delormier T, Potvin L, Paradis G, McComber A. Developing a Code of Research Ethics for research with a Native community in Canada: a report from the Kahnawake Schools Diabetes Prevention Project. *Int J Circumpolar Health.* 1998; 1998; 5757(suppl 1):38–40. [PubMed: 10093242]
38. Macaulay AC, Delormier T, McComber AM, et al. Participatory research with native community of Kahnawake creates innovative Code of Research Ethics. *Can J Public Health.* 1998; 89(2):105–108. [PubMed: 9583251]
39. Poland BD, Tupker E, Breland K. Involving street youth in peer harm reduction education: the challenges of evaluation. *Can J Public Health.* 2002; 93(5):344–348. [PubMed: 12353454]
40. Sampsel CM. Nickel-and-dimed in America: underserved, understudied, and underestimated. *Fam Community Health.* 2007; 30(1 suppl):S4–S14. [PubMed: 17159631]
41. Schell LM, Tarbell AM. A partnership study of PCBs and the health of Mohawk youth: lessons from our past and guidelines for our future. *Environ Health Perspect.* 1998; 106(suppl 3):833–840. [PubMed: 9646046]

42. Maiter S, Simich L, Jacobson N, Wise J. Reciprocity: an ethic for community-based participatory action research. *Action Res.* 2008; 6(3):305–325.
43. Ham M, Jones N, Mansell I, Northway R, Price L, Walker G. “I’m a researcher!” Working together to gain ethical approval for a participatory research study. *J Learn Disabil.* 2004; 8(4): 397–407.
44. Corder A, Ciptel D, Brown P, Morello-Frosch R. Reflexive research ethics for environmental health and justice: academics and movement-building. *Soc Mov Stud.* 2012; 11(2):161–176. [PubMed: 22690133]
45. Mitchell TL, Baker E. Community-building versus career-building research: the challenges, risks, and responsibilities of conducting research with aboriginal and Native American communities. *J Cancer Educ.* 2005; 20(1, suppl):41–46. [PubMed: 15916520]
46. Jacklin K, Kinoshameg P. Developing a participatory aboriginal health research project: “only if it’s going to mean something.” *J Empir Res Hum Res Ethics.* 2008; 3(2):53–67. [PubMed: 19385745]
47. Khanlou N, Peter E. Participatory action research: considerations for ethical review. *Soc Sci Med.* 2005; 60(10):2333–2340. [PubMed: 15748680]
48. Bastida EM, Tseng TS, McKeever C, Jack L Jr. Ethics and community-based participatory research: perspectives from the field. *Health Promot Pract.* 2010; 11(1):16–20. [PubMed: 20038649]
49. Harding A, Harper B, Stone D, et al. Conducting research with tribal communities: sovereignty, ethics, and data-sharing issues. *Environ Health Perspect.* 2012; 120(1):6–10. [PubMed: 21890450]
50. Shannon K, Bright V, Allinott S, Alexson D, Gibson K, Tyndall MW. Maka Project Partnership. Community-based HIV prevention research among substance-using women in survival sex work: the Maka Project Partnership. *Harm Reduct J.* 2007; 4:20. [PubMed: 18067670]
51. Salmon A, Browne AJ, Pederson A. “Now we call it research”: participatory health research involving marginalized women who use drugs. *Nurs Inq.* 2010; 17(4):336–345. [PubMed: 21059151]
52. Smith E, Ross F, Donovan S, et al. Service user involvement in nursing, midwifery and health visiting research: a review of evidence and practice. *Int J Nurs Stud.* 2008; 45(2):298–315. [PubMed: 17161402]
53. Smith R, Monaghan M, Broad B. Involving young people as co-researchers: facing up to the methodological issues. *Qual Soc Work.* 2002; 1(2):191–207.
54. Williamson GR, Prosser S. Action research: politics, ethics and participation. *J Adv Nurs.* 2002; 40(5):587–593. [PubMed: 12437608]
55. Wolf LE. The research ethics committee is not the enemy: oversight of community-based participatory research. *J Empir Res Hum Res Ethics.* 2010; 5(4):77–86. [PubMed: 21133789]
56. Flicker S, Worthington CA. Public health research involving aboriginal peoples: research ethics board stakeholders’ reflections on ethics principles and research processes. *Can J Public Health.* 2012; 103(1):19–22. [PubMed: 22338323]
57. Giese-Davis J. Community/research collaborations. Ethics and funding. *Clin Psychol Sci Pract.* 2008; 15(2):149–152.
58. Guta A, Nixon S, Gahagan J, Fielden S. “Walking along beside the researcher”: how Canadian REBs/IRBs are responding to the needs of community-based participatory research. *J Empir Res Hum Res Ethics.* 2012; 7(1):15–25. [PubMed: 22378131]
59. Malone RE, Yerger VB, McGruder C, Froelicher E. “It’s like Tuskegee in reverse”: a case study of ethical tensions in institutional review board review of communitybased participatory research. *Am J Public Health.* 2006; 96(11):1914–1919. [PubMed: 17018816]
60. Sharp RR, Foster MW. Community involvement in the ethical review of genetic research: lessons from American Indian and Alaska Native populations. *Environ Health Perspect.* 2002; 110:145–148. [PubMed: 11929722]
61. Shore N, Drew E, Brazauskas R, Seifer SD. Relationships between community-based processes for research ethics review and institution-based IRBs: a national study. *J Empir Res Hum Res Ethics.* 2011; 6(2):13–21. [PubMed: 21680973]

62. Silka L, Cleghorn GD, Grullon M, Tellez T. Creating community-based participatory research in a diverse community: a case study. *J Empir Res Hum Res Ethics*. 2008; 3(2):5–16. [PubMed: 19385742]
63. Ramsey CA, Quearry B, Ripley E. Community consultation and public disclosure: preliminary results from a new model. *Acad Emerg Med*. 2011; 18(7):733–740. [PubMed: 21729187]
64. Mchener L, Cook J, Ahmed SM, Yonas MA, Coyne-Beasley T, Aguilar-Gaxiola S. Aligning the goals of community-engaged research: why and how academic health centers can successfully engage with communities to improve health. *Acad Med*. 2012; 87(3):285–291. [PubMed: 22373619]
65. Boyer BB, Mohatt GV, Pasker RL, Drew EM, McGlone KK. Sharing results from complex disease genetics studies: a community based participatory research approach. *Int J Circumpolar Health*. 2007; 66(1):19–30. [PubMed: 17451131]
66. Mohammed SA, Walters KL, LaMarr J, Evans-Campbell T, Fryberg S. Finding middle ground: negotiating university and tribal community interests in community-based participatory research. *Nurs Inq*. 2012; 19(2):116–127. [PubMed: 22530859]
67. Williams V, St Quintin P, Hoadley S. “Take your partners”: reflections on a partnership project in learning disability research. *Action Res*. 2006; 4(3):295–314.
68. Deeds BG, Castillo M, Beason Z, Cunningham SD, Ellen JM, Peralta L. An HIV prevention protocol reviewed at 15 national sites: how do ethics committees protect communities? *J Empir Res Hum Res Ethics*. 2008; 3(2):77–86. [PubMed: 19385747]
69. Brody JG, Morello-Frosch R, Brown P, et al. Improving disclosure and consent: “Is it safe?”: new ethics for reporting personal exposures to environmental chemicals. *Am J Public Health*. 2007; 97(9):1547–1554. [PubMed: 17666695]
70. Hsieh H-F, Shannon SE. Three approaches to qualitative data content analysis. *Qual Health Res*. 2005; 15(9):1277–1288. [PubMed: 16204405]
71. Jones L, King L, Wilson C. A literature review: factors that impact on nurses’ effective use of the Medical Emergency Team (MET). *J Clin Nurs*. 2009; 18(24):3379–3390. [PubMed: 20487489]

TABLE 1**Articles in Literature Review Discussing The Meaning of the Belmont Principles in Community-Based Participatory Research**

Principle	Citations, No.^a
Community autonomy	30
Respect for community needs, interests, values, strengths, culture	25
Joint interpretation of findings and dissemination of results	7
Voluntary community participation in research	5
Respect for dignity and recognition of worth	5
Social and community justice	18
Burden of participation and research benefits should be equitably and fairly distributed in community	7
Community benefits should be prioritized	7
Negotiation of compromises between community partners and researchers	3
Justice for all people	2
Community beneficence	17
Risk and benefits should be evaluated for community researchers and community at large	14

Note. The 1979 Belmont Report outlined 3 ethical principles for biomedical research: autonomy, beneficence, and justice.³ Only articles that explicitly mentioned either autonomy, beneficence, or justice as components of ethical community-based participatory research are included in this table.

^aTwo articles by Macaulay et al.,^{38,39} which report on similar features of the same study, are tallied as 1 article.

TABLE 2**Articles in Literature Review Discussing Components of Ethical Community-Based Participatory Research**

Component	Citations, No.^a
Community collaboration (involvement, mutuality, reciprocity, shared leadership, trust, transparency, authenticity)	54
Community significance	44
Community relevance	39
Community initiation	33
Community return	35
Community benefit	22
Social action orientation	19
Community capacity building	17
Sustainability	5
Community control	23
Joint ownership of data	18
Strength-based focus	9

^aTwo articles by Macaulay et al.,^{38,39} which report on similar features of the same study, are tallied as 1 article.

TABLE 3

Articles in Literature Review Discussing Ethical Challenges of Community-Based Participatory Research

Ethical Challenge	Citations, No. ^a
Insider–outsider tensions	24
Differing assumptions, perceptions, expectations; conflicting agendas; mistrust from communities	17
Power differentials between researchers and community; differences in cultural values; racism; seeking equality between partners; power/coercion	17
Protecting communities	22
Challenges with consenting community; addressing collective implications of studies; determining risk–benefit ratio	18
Confidentiality/anonymity is challenging in many closed communities and may be inappropriate; threats to privacy of health information	8
Community representation (challenges determining who is community, who speaks for community, who should sit on boards; what to do when working with multiple communities or divided communities)	15
Data sharing; reporting and using results (dealing with unflattering data or unclear results, producing tangible community benefits, defining data ownership and publication rights)	12
Working with IRBs (IRBs are unfamiliar with CBPR practices; may hold inapplicable assumptions about research methods and data ownership, be unfamiliar with dynamic nature of researcher–participant interaction, assume protocol can be stipulated in advance)	12
Managing dual roles as community members and researchers (conflicting loyalties, shifting roles of participants)	8
Practicalities (time investment, costs)	6
Challenges of community commitment (community partners may pull out, may not maintain interest and compromise study, may be hard to keep track of)	5
Cyclical, dynamic, iterative, and evolving nature of CBPR (poses problems for establishing clear ethical codes or guidelines; ethics cannot be predetermined)	5
Lack of explicit guidelines (lack of published examples on how to ensure ethical integrity in CBPR; no defined method for determining study effectiveness)	3
Ethics assumed (CBPR is seen to be ethical response; ethical issues may thus be neglected)	3
Misconduct occurs under ethical guise of CBPR (using community members to gather data only; not letting community know about outcomes)	2
Resource and funding challenges (CBPR is unrecognized by funding agencies but requires considerable resources)	2

Note. CBPR = community-based participatory research; IRB = institutional review board.

^aTwo articles by Macaulay et al.,^{38,39} which report on similar features of the same study, are tallied as 1 article.

TABLE 4

Articles in Literature Review Discussing Ways to Ensure Ethical Community-Based Participatory Research

Strategy	Citations, No. ^a
Engage community (all partners must be equally included in the project at all stages; community values and expectations need to be understood)	30
Prioritize transparency	29
Open, honest, and continual communication	17
Formalized research agreements/guidelines and data-sharing protocols	17
Develop community advisory boards (include community members and encourage discussion of all study phases, e.g., determining research questions and interpreting data; enable community relevance and sensitivity)	23
Educate IRBs about CBPR and community about review process (review process requires flexibility, may need to happen at multiple stages of project, and may benefit if done in concert with academic and community researchers)	13
Develop community review boards (ensure that community needs and priorities are addressed)	11
Promote professional/ethical development (reflexive research ethics; reliance on professional morality; continual reflection and cultural humility)	9
Carefully consider study personnel (hire bilingual study personnel from community who are familiar with culture)	4
Change funding priorities and procedures (increase funds for community partners; include in funding proposals adequate time for partnership building; fund pilots of 2–3 y for relationship development)	4
Maintain rigorous research design (stipulate rigorous design early; emphasize standardized procedures)	4

Note. CBPR = community-based participatory research; IRB = institutional review board.

^aTwo articles by Macaulay et al.,^{38,39} which report on similar features of the same study, are tallied as 1 article.