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## Developing a Family-Based HIV Prevention Intervention in Rural Kenya: Challenges in Conducting Community-Based Participatory Research

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### Abstract

Community-based participatory research (CBPR) introduces new ethical challenges for HIV prevention studies in low-resource international settings. We describe a CBPR study in rural Kenya to develop and pilot a family-based HIV prevention and mental health promotion intervention. Academic partners (APs) worked with a community advisory committee (CAC) during formative research, intervention development, and a pilot trial. Ethical challenges emerged related to: negotiating power imbalances between APs and the CAC; CAC members' shifting roles as part of the CAC and wider community; and anticipated challenges in decision making about sustainability. Factors contributing to ethical dilemmas included low access to education, scarcity of financial resources, and the shortage of HIV-related services despite high prevalence.

### Keywords

HIV prevention; community-based participatory research; ethical challenges; adolescents; children; families; mental health; Kenya

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COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR) integrates the goals of community members and academic researchers to establish an equal partnership for effecting positive change within a community (Ross et al., 2010). Academic and community partners have different roles that serve to maximize the strengths and expertise that they bring to the research process (ibid.). Major roles of community participants include educating academic partners (APs) about cultural norms and values and drawing on their networks of relationships within the community to facilitate the progress of a study (Molyneux, Kamuya, & Marsh, 2010). Academic partners can then contribute expertise in research methodology and academic knowledge of the literature and theory related to the topic of interest. The most effective

CBPR fosters collaboration at the outset of the research, facilitating the bidirectional flow of knowledge and skills throughout the research process (Bishop, 1994, 1996; Israel et al., 1998).

In HIV prevention research, researcher-community partnerships have proven beneficial, particularly given the strong influence of context-specific factors on sexual behavior (Marcus et al., 2004; Rhodes, Malow, & Jolly, 2010; Rhodes et al., 2006; Williams, Palar, & Derose, 2011). Interventions are much more likely to be effective if designed within the context of community norms and with an awareness of the environmental constraints that influence the opportunities for HIV preventative health behaviors. As documented by Corbie-Smith and colleagues (2011), CBPR can be useful in developing such tailored interventions. Other advantages of CBPR more generally are also important in HIV research, including: increased external validity of data (Miller & Shinn, 2005; Hohmann & Shear, 2002), empowerment of communities (Wallerstein & Duran, 2010), and employment opportunities for community members as part of research studies (Nyden & Wiewel, 1992).

While most published CBPR studies in the field of HIV prevention are situated within the United States, CBPR has also been conducted in low- and middle- income countries. In studies conducted by outside researchers, participatory methods can be especially valuable to prevent the “colonizing” characteristics of some international research in which Western values are imposed, the research is not understood by participants, and studies lead to very little or no benefits for communities (Minkler, 2004; Tervalon & Murray-Garcia, 1998). CBPR methods can mitigate these problems by focusing on action-oriented studies driven by a community’s interests and needs (Fals-Borda, 2006; Lesser & Ocos-Sanchez, 2007).

The tenets of CBPR are very much in line with the Belmont principles (Belmont Report, 1979) for ethical research and help address some of the challenges that arise when trying to adhere to these principles in international low-resource settings. CBPR is designed to improve beneficence through positive action in communities and to prevent unforeseen risks and injustices that arise from inadequate contextual knowledge. Interaction with communities increases probability that consent will be truly informed, which is difficult to achieve in contexts where language barriers exist and populations have little exposure to research. The Belmont principles, coupled with CBPR ethical frameworks (Emanuel et al., 2004), provide the foundation for the analysis of ethical issues in this paper.

Many ethical challenges in CBPR have been identified, some of which are intensified when working in international, low-resource settings on sensitive topics such as HIV and mental health. Power imbalances between researchers and community members are difficult to overcome (e.g., Bell & Standish, 2005; Israel et al., 2001), and the use of Western approaches to research can put academic researchers in a position of greater empirical knowledge and power from the beginning (Varcoe et al., 2011). Further, the risk of exploitation is high in low-income countries, particularly in public health research, as resources and access to healthcare are often limited. This places heightened value on new interventions and on ensuring that they are maximally beneficial and sustainable if effective (Emanuel et al., 2004). Emanuel and colleagues (2004) presented ethical guidelines specific to participatory research in developing countries that emphasize taking culture into account, targeting top-priority health needs, and ensuring that research designs allow for the delivery of needed health services and fair selection of recipients.

In this paper, we describe the ethical challenges we encountered during a CBPR study to develop and evaluate an HIV prevention and mental health promotion intervention in rural Kenya. To begin, we provide a brief overview of the project and context. The remainder of

our discussion examines the ethical challenges we experienced and offers insights and recommendations based on our learning.

## Project Context and Methods

We conducted this study in a rural community located on the shores of Lake Victoria in the Nyanza Province of Kenya. Nyanza has high rates of poverty and the highest HIV rate in Kenya at 15.3%, in part due to transactional sex associated with the fishing industry (Kenya AIDS Indicator Survey, 2007; Béné & Merten 2008). In this community, resources—financial, material, and educational—are scarce, with fishing being the primary source of income.

The goal of the study was to develop, implement, and evaluate an intervention targeting family and community factors influencing sexual risk behavior and mental health among adolescents and their families. We used CBPR methodology with the goals of (a) targeting the specific risk and protective factors that were the highest priority for the community, (b) developing an intervention anchored in local culture and norms, and (c) building a community-based team that could sustain the intervention if effective. Our approach was based on the principles of CBPR as presented by Israel and colleagues (1998), with particular emphasis on engaging in a co-learning process with community members, building on the strengths of the community, and addressing the health problems of HIV and mental health from a positive, ecological systems perspective. Community partners were engaged in all phases of the research, including: (a) formation of the community partnership, (b) a formative mixed-methods assessment of needs and resources, (c) intervention development, and (d) intervention implementation within a randomized controlled pilot trial.

Our partnerships included WISER: Women's Institute for Secondary Education and Research ([www.wisergirls.org](http://www.wisergirls.org)), a community nongovernmental organization, village chiefs, teachers, hospital staff, and church leaders. We collaborated to develop the initial research questions for the formative assessment and to recruit 20 community members for a formal community advisory committee (CAC) representative of different sectors (see Table 1). To prepare for collaborative analysis of the formative data and intervention development, we held a series of in-person meetings and electronic communications to facilitate knowledge exchange between the APs and CAC. The APs provided an orientation to research methodology and presented material on empirically supported methods for HIV prevention, including academic literature. The CAC members engaged in discussion with the APs about these materials, particularly related to how the information from the broader field of HIV prevention may apply to their community.

Following data collection and statistical analysis of the formative assessment, the APs and CAC collaboratively interpreted these results (see Puffer et al., 2011). This was particularly valuable for statistical results that were counterintuitive; the CAC provided interpretations that were quite parsimonious, but only in light of their knowledge of the culture and local norms. After analysis, the APs and CAC held a series of meetings to identify targets of the intervention and to develop an implementation plan. The result was a church-based intervention for families that focused on poverty, emotional support, and skills and communication related to HIV prevention. The team conducted intervention development workshops that included CAC members and other adolescents and caregivers from the community. The APs introduced evidence-based intervention strategies to provide a basic framework for these sessions, and the groups developed the activities, examples, and formats through which to implement those strategies. A pilot randomized controlled trial was then conducted with 100 families across four churches. During the trial, many CAC

members took on roles as intervention facilitators or survey enumerators, while APs took on support and management roles.

## Ethical Challenges

At several points in the study, we faced ethical dilemmas related to: (a) negotiating power imbalances between APs and CAC members, (b) responding to shifts in CAC members' roles within the committee and community, and (c) making decisions and plans for sustainability. Our analysis of these issues was guided by the Belmont principles and the ethical principles specific to CBPR in developing countries outlined by Emanuel and colleagues (2004). We considered options based on which choices would maximize the benefits to the CAC and community, remain the most consistent with their needs and priorities, and be most respectful and just within this culture and context.

**POWER IMBALANCES**—A central challenge in this project was creating and maintaining an equal power balance between the APs and the CAC, in large part because of the stark resource disparities, both in terms of educational background and financial resources. This was most challenging during the initial formation of the partnership and the pilot trial. The specific issues were different in these two stages, but the central dilemma was the same: protecting the equal power balance versus providing information and funding to the CAC at the cost of setting up hierarchical relationships. During partnership formation, the APs questioned the extent to which we should train the CAC on research methods and current evidence in the field of HIV prevention. Our goal was to give CAC members the background information they would need to contribute to intervention development based on both local knowledge and outside sources, rather than prescribing them the narrower role of only contributing based on their existing knowledge of the community. The intent was to equip the CAC to be full partners in choosing the evidence-based elements they expected to succeed in the community. CAC members expressed interest in this and saw it as an educational opportunity.

A significant risk, however, was that information flow would be largely unidirectional, setting up a teacher-student relationship inconsistent with the CBPR value of equal power sharing. Further, the technical and academic nature of the material would be unfamiliar to most of the CAC, and some of the information would challenge myths and beliefs held by some of the members. We knew that this could reinforce the power imbalance, and might have suggested that APs rejected local values and perspectives. The eventual decision was to accept these risks and to provide in-depth information. Our rationale was that the educational value and potential to improve equality during the later phases of the project maximized benefits to the CAC and was consistent with the CAC's goals for the partnership. We balanced the teaching from the APs with asking the CAC to educate APs about the local context at the same time. This seemed to lessen the power differential but did not eliminate it, and as a result we made a concerted effort to shift the dynamics in the following phases, data analysis and intervention development.

A similar challenge arose during the pilot trial when we prepared to hire enumerators and intervention facilitators. Many CAC members were unemployed and motivated to move into these positions. The APs agreed they were well qualified, but were wary about the employer-employee relationship dynamics this would create, as the APs were to oversee data collection, implementation plans, and budget. One major risk was that CAC members would become inhibited in their advisory roles, hesitating to voice opinions in order to avoid perceived insubordination. There was a fear among the APs that they would be hesitant to raise concerns about the ways in which topics of sexuality were addressed—a very sensitive issue on which APs needed candid input. This posed risks to the true check-and-balance role

of the CAC. Despite this, not employing the CAC members seemed more harmful and disruptive, as it would have denied the CAC members of resources after they had dedicated significant time and effort. In higher resource settings, it is more likely that the majority of community advisors would be employed, in which case research staff might be a separate group. In this setting, however, hiring the members seemed the more ethical option in terms of respecting the priorities of the community members and responding to clear, immediate needs.

**SHIFTS IN ROLES OF CAC MEMBERS**—By joining the CAC, members took on new roles and responsibilities that, for many, were unfamiliar. The composition of the CAC, which included men and women of varying social positions, brought together people that otherwise would not have worked together and whose interactions would typically be structured by their relative status and power in the community. Challenges emerged early, as the cultural and social norms of the community were reflected in the ways members interacted; for example, female members deferred to male members and some males had difficulty taking feedback from their female counterparts. Because elders are revered and respected in Kenyan society, younger team members were hesitant to disagree with older members, particularly older males. These dynamics became particularly evident when some female and younger members took on leadership responsibilities within the CAC related to their expertise in specific skills (e.g., teaching). Their ability to lead was sometimes hindered by these prescribed roles.

The APs' initial concern was that those with higher status in the community would have more decision-making power in the partnership, which threatened the goal of ensuring equality as a key principle of CBPR. This was particularly important because some of these power differences contribute to the HIV prevalence in this community; women's lack of power in sexual decision making and the vulnerability of youth, particularly females, put them at greater risk for HIV (Luginaah et al., 2005). Thus, the APs struggled to help balance power within the team but faced ethical questions in trying to remain culturally sensitive. CAC members who had less social power also faced a similar dilemma. They recognized the potential risks of allowing the hierarchy to be disrupted, such as being perceived as disrespectful or as trying too hard to identify with the outsiders, the APs, rather than adhering to cultural expectations. The challenge was to strike a balance between purposefully disrupting community norms and respecting them. Primarily, to promote equality, the APs gave equal priority to all members for positions of higher responsibility, as evaluation and management were roles of the APs, but did not challenge members' decisions to respect hierarchical norms in other ways (e.g., female members serving food to male members during group dinners).

The new roles of CAC members also posed challenges in their interactions with the broader community. In this small community, the involvement of the CAC members in the study was widely known, resulting in both benefits and challenges. CAC members were seen as role models and leaders within the community, and were therefore respected by some community members. In contrast, other community members expressed jealousy or suspicion due to their involvement and were skeptical about the study. These reactions sometimes put CAC members in the position of defending themselves and the project. Additionally, as community members began to perceive CAC members as leaders, they began to ask CAC members for services beyond the scope of the intervention (e.g., medical care) that they could not provide. CAC members also were sometimes perceived as responsible for the fact that the intervention was only implemented with a limited number of families during the pilot study. This pressure was intensified because of the high HIV prevalence in the community and abundant need for HIV prevention and treatment.



The sensitive content of the study also posed risks to the CAC members' reputations. During sessions, CAC members encouraged participants to talk openly about sex, HIV, and family relationships—even giving condom use demonstrations in church settings. In short, they promoted behaviors considered unacceptable by some and unfamiliar to almost all. Further, HIV-related information presented in the intervention challenged misconceptions held in the community, sometimes requiring CAC members to disagree publicly with respected congregation members.

While some of these consequences were not particularly surprising, they were consequences that CAC members and APs did not consider fully at the beginning of the project. For some CAC members, this led to the ethical dilemma of continuing their work to make a positive contribution to the community versus protecting their reputations, positive social relationships, or their other roles in the community. A complicated issue for the APs was to examine how responsible they were for minimizing the challenges the CAC members faced. It is clear that researchers should follow the principle of beneficence and least harm, and it is clear that researchers must protect the rights of human subjects. However, CAC members are not “subjects,” but research partners. The lines seemed blurred between community researchers and participants, as it seemed that APs did carry some additional responsibility because they initiated the research in this community and the formation of the CAC. The APs' response to this dilemma was to initiate discussions about the challenges the members were facing to identify any serious problems with the broader community, to advise and brainstorm solutions, and to encourage CAC members' autonomy by reminding them that they were free to change or decrease their involvement in the study if the costs began to outweigh the benefits. No CAC members left because of this reason, though there were some cases in which CAC members decided not to interview or facilitate at churches where they had close relatives to avoid the dual roles of teacher and family member.

**SUSTAINABILITY: DECISIONS AND PLANNING**—Results of the trial will be interpreted collaboratively by the APs and CAC, and both partners will be involved in discussing next steps. At the time of writing this article, data analysis is ongoing. If results indicate that the intervention is beneficial, we must consider potential challenges regarding how the intervention will be sustained and the degree of responsibility the APs and CAC members possess to ensure sustainability. The intervention was developed with sustainability in mind, with the vision that churches could adopt this program as they do their other activities that are facilitated by church volunteers. It is impossible to predict, however, how easy or difficult implementing that model will prove to be.

The ethical question for the APs is not whether or not we are responsible for supporting sustainability, as we decided from the beginning to collaborate with the community to develop a sustainability plan. However, we did not decide from the beginning how responsible APs were for obtaining funding and for what length of time APs would remain actively involved before giving full financial and operational responsibility to the community. The CAC members have a similar dilemma. They must also decide how much time and effort they are obligated and able to give, particularly as their financial compensation would decrease or disappear after project completion or if there is no further funding. It is unclear at what point the broader community must engage to share the responsibility. We expect the main challenge to gaining buy-in will be that facilitators will be volunteers, as the community knows that the CAC members were paid for their roles in implementation during the research phase. This problem highlights the cyclical nature of ethical dilemmas in this type of work; our previous decision to pay the CAC members for their time and effort on the project may now cause a barrier to sustaining the program.

These ethical sustainability questions will become more difficult in the case of null or ambiguous results, particularly since the local perception is that the intervention was beneficial for both family well-being and HIV prevention. If statistical results do not, or only partially, corroborate this, the APs will face the dilemma of whether to partner with the community to sustain the intervention, prioritizing their ownership of the program, or delay continuation, using any available resources to revise the intervention instead to attempt to increase its efficacy. In making these decisions, it will be difficult to maintain an equal power balance between the APs and CAC members since community members have very few potential sources of funding. This places the CAC in a position of dependence and the APs in a position of responsibility, both of which can be difficult. The challenge will be to recognize the limits and constraints facing both parties while also prioritizing a joint decision-making process.

## Discussion

CBPR methods have the potential to raise the ethical standards of HIV prevention research in developing countries, but only if APs and community members continue to evaluate and prepare for the challenges to adhering to CBPR and ethical research principles in these very low-resource settings (Emanuel et al., 2004). Case studies examining the unique ethical dilemmas across types of CBPR studies are important for pushing the field toward more nuanced and creative solutions. In the current study, three characteristics of the community setting emerged as strong contributors to the ethical dilemmas we have described: (a) limited access to education, (b) scarce financial resources and employment opportunities, and (c) high HIV prevalence within the community. These are characteristics shared across many developing country settings where HIV prevention research is most needed.

In settings with very few educational opportunities, community partners are unlikely to have had adequate access to HIV-related information and are unlikely to have had exposure to research studies and methods. While APs conducting CBPR usually do bring more of this research knowledge, community partners in higher-resource settings often have a foundational understanding of the research process and access to basic information about HIV; they can therefore anticipate the basic structure and sequence of a project. When this foundation is absent, as in our study or those in similar contexts, we would argue that emphasizing training and information sharing is empowering. In our experience, our community partners held this view as well. The training process can be facilitated in a way that is consistent with Israel et al.'s (1998) framework on “multiple ways of knowing” (p. 175); academic and local knowledge can be recognized as equally important, and a goal of the partnership can be mutual exchange of both. In their analysis of CBPR in research with Native American populations, LaVeaux and Christopher (2009) report similar observations and describe training as part of the empowering co-learning process that allows community partners to fully engage in the research process. Further, the risks of not providing training in this type of setting seem to mirror the risks of enrolling participants without consent—a clear requirement for ethical CBPR (Flicker et al., 2007). Lack of informed consent for community partners could mean that partners are not given the chance to evaluate the potential risks (e.g., carrying too much responsibility in the community, implementing a controversial intervention).

If it is the most ethical choice to provide training to partners with low access to education and information, the challenge is to determine how to do this while maintaining as much equality as possible in the partnership. Few examples have been published related to specific ways that APs share information with communities at the beginning of a partnership and how they may avoid the power imbalance during the process, though some strategies have been described. Often it seems that researchers are working with community partners to

establish guiding documents to set up the project, which would include information about methodology and the topic of interest (Ross et al., 2010; Silka et al., 2008). This strategy is less promising, however, in communities where educational opportunities are scarce and literacy is low. In CBPR for HIV prevention in a rural African American community, Corbie-Smith et al. (2011) describe hiring an external organization to hold workshops for both community and academic partners. Such a model may allow for communication of new knowledge without elevating the APs to a teaching position. Another potential model may be an entirely time-balanced process in which equal time is given for APs to teach from academic knowledge and for community partners to teach from local knowledge. This may be quite time consuming, but would provide an equal exchange of information and give each partner the information needed to determine, with full autonomy, whether to proceed.

In addition to limited access to education, poverty is widespread in developing countries where HIV prevalence remains high and is a powerful influence on the research process. Economic disparities between APs and community members in these settings are usually stark. From a CBPR perspective, community partners are researchers and ideally should co-lead the fieldwork rather than conducting the fieldwork under the leadership and employment of the APs. Being employed creates a power dynamic and an incentive structure that can impede joint decision making and pose a barrier to the healthy skepticism that community members can often bring to a study. In a resource-poor context, however, community partners are very likely to want to be compensated for their time and effort and to feel more empowered in the position of employee than in the role of advisor.

Most CBPR studies do not specify if and how much partners are compensated, though some mention that the time requirement can become burdensome for partners (Lantz et al., 2001). Others reference hiring external staff to manage the partnership process, which demands less from community advisors (Silka et al., 2008; Corbie-Smith et al., 2011). This was not a problem in this study, however, as many CAC members were glad to have productive activities to fill their time given so few job opportunities. When this is the case, while not compensating partners may preserve equality in some ways, it may also exploit partners' time and remove a key potential benefit of the research.

For studies in which researchers decide to compensate community advisors for fieldwork, the need for structured decision-making processes is important. The advisory role of community partners may be better preserved if specific times and settings are reserved for discussion and feedback related to research decisions that are completely separate from meetings and activities related to employee tasks or responsibilities. The goal would be to separate the advisor roles from the employee roles of the partners—and the academic partner and employer roles of the APs—to shift back into the power balance necessary for collaborative decision making.

Poverty within the wider community also contributes to the ethical challenges related to sustainability. In a setting with so few services and resources, community members are very aware of even small-scale programs. In this study, only a very small segment of the population received the intervention (i.e., 100 families across four churches). Random selection of churches was used for transparency and fairness; however, the ethical question was whether to introduce a resource into a community with very few community-based programs without a guarantee of larger-scale service provision. As this is a common challenge, we designed the program to be implemented at very little cost and to be integrated into existing, strong social settings—churches—that already provide programs for families with no paid staff and minimal materials. This plan was consistent with a review of heart health interventions documenting that requiring no paid staff was a characteristic associated with long-term sustainability (O'Loughlin et al., 1998). The APs envisioned



completing the study and transferring leadership to the community partners, with the ultimate goal of a community-wide intervention run and managed completely by the community.

This model is likely to be challenging in this study, however. In this geographically isolated community with such widespread poverty, this project was viewed as two interventions in one: (a) a social service to help families prevent HIV and (b) a new potential source of jobs, education, and training through ongoing connections with wealthy American institutions. Thus, removing the connections to the APs and transitioning to a church volunteer-based implementation model will be a difficult adjustment for the community partners, as it will only sustain part of what they perceive the intervention to be. This is likely to be a common dynamic in CBPR in isolated, developing country settings, where the relationships built are as important, if not more important, than the public health intervention itself.

Lastly, this study highlighted the particular challenges of conducting CBPR focused on one of the most urgent unmet needs of a community—in this case, HIV. A sense of urgency from the community can contribute to the high profile nature of a study and perhaps create undue pressure on community partners. As research clearly should be addressing the most pressing problems facing communities (Emanuel et al., 2004), the challenge is to develop strategies to be transparent with communities about the limits of the study, to support community partners to respond to reactions from the community, and to develop plans to sustain effective interventions in the communities where they were studied. Underlying all of these ethical challenges is the fact that HIV prevention research is needed in the lowest resource settings where HIV prevalence is highest. The potential impact of identifying effective community-based prevention strategies is a compelling reason to conduct this research, even in light of the very significant ethical challenges involved.

## Best Practices

Conducting CBPR in low-resource, international studies may be considered a best practice in and of itself. Building a partnership with community members greatly increases the probability that the research will be of ultimate benefit to a community. Researchers should recognize that understanding the culture of a community is essential for conducting ethical research and should prioritize this learning at the beginning of community partnerships. This is particularly important in HIV prevention research, as cultural factors often influence sexual behavior that prevention interventions address.

The process of learning from community partners about the local context and culture should be combined with a process of introducing them to the research process and the ways that the research fits within the broader field of study. Through this bidirectional process, both the community and academic partners have the opportunity to give “informed consent” before beginning the research with full knowledge of the potential risks and benefits. This will require researchers’ time and effort to develop structured ways in which to exchange information prior to beginning a study.

Providing complete and transparent information about a research study should not be limited to potential community advisors. Researchers should also share responsibility with the community partners to educate the broader community about the limits of any intervention or service provided, including information about whether or not the intervention will be sustained long term. This is particularly important when research is conducted in communities where services and program are scarce and when interventions address a serious problem within a community. When this type of research is conducted, researchers and community partners should have clear plans for making decisions about sustainability at the beginning of the study.

## Research Agenda

A productive goal for research on the ethical challenges in CBPR would be to establish guidelines for CBPR studies on HIV prevention that are empirically and ethically supported. Establishing these guidelines would require several steps: formalizing and planning models of CBPR for HIV prevention in advance, establishing meaningful indicators of the quality and success of community partnerships, and collecting systematic data to provide evidence on the models of CBPR methodology that are most effective in HIV prevention. These models can then be evaluated in low-resource international settings.

To build the empirical base for the creation of evidence-based models, HIV prevention researchers should prioritize documenting and sharing methods for mitigating ethical risks. This is especially important as CBPR studies evaluating HIV prevention interventions in low-income country settings are becoming increasingly frequent. Consequently, more than ever before, there exists information and unique experiences with ethical challenges faced in the field. Despite the fact that approaches to ethical challenges will often be context specific, it is important to publish and present on methods for mitigating risks to inform contextually similar studies.

## Educational Implications

Students often focus on developing their research skills within a particular content area and learn research ethics as a separate topic. We believe that our study, in addition to similar studies, exhibits how a more effective approach might be to prioritize instruction related to ethical challenges that are specific to certain topic areas. For students focusing on HIV-related research, considering these ethical challenges early in the learning process and reading about how these issues have been handled in other studies could improve their ability to prepare for these challenges in designing their first studies. Often students are required to complete mock research proposals in advanced research methods courses. We would recommend that those assignments require students to include a section on ethical considerations specific to their topic, including relevant literature that has been published on ethics in their particular field. Further, those conducting CBPR and who have worked to resolve ethical dilemmas in the field should provide continuing education opportunities focused on ethics for both students and other established researchers alike.

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## References

- Bell J, Standish M. Communities and health policy: A pathway for change. *Health Affairs*. 2005; 24(2):339–342. [PubMed: 15757917]
- Belmont Report. [Retrieved December 31, 2012] The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research. 1979. from [hhs.gov/ohrp/humansubjects/guidance/belmont.html](https://www.fda.gov/ohrt/humansubjects/guidance/belmont.html)
- Béné C, Merten S. Women and fish-for-sex: Transactional sex, HIV/AIDS and gender in African fisheries. *World Development*. 2008; 36(5):875–899.
- Bishop R. Initiating empowering research? *New Zealand Journal of Education Studies*. 1994; 29(1): 175–188.
- Bishop, R. Addressing issues of self-determination and legitimation in Kaupapa Maori research. In: Webber, B., editor. *Research perspectives in Maori education*. New Zealand Council for Educational Research; Wellington: 1996. p. 143-160.
- Corbie-Smith G, Adimora AA, Youmans S, Muhammad M, Blumenthal C, Ellison A, et al. Project GRACE: A staged approach to development of a community-academic partnership to address HIV in rural African American communities. *Health Promotion Practice*. 2011; 12(2):293–302. [PubMed: 20685913]
- Emanuel EJ, Wendler D, Killen J, Grady C. What makes clinical research in developing countries ethical? The benchmarks of ethical research. *Journal of Infectious Diseases*. 2004; 189(5):930–937. [PubMed: 14976611]
- Fals Borda O. The North-South convergence: A 30-year first-person assessment of PAR. *Action Research*. 2006; 4(3):351–358.
- Flicker S, Travers R, Guta A, McDonald S, Meagher A. Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*. 2007; 84(4):478–493. [PubMed: 17436114]
- Hohmann AA, Shear MK. Community-based intervention research: Coping with the “noise” of real life in study design. *American Journal of Psychiatry*. 2002; 159(2):201–207. [PubMed: 11823259]

- Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*. 1998; 19:173–202.
- Israel BA, Schulz AJ, Parker EA, Becker AB. Community-based participatory research: Policy recommendations for promoting a partnership approach in health research. *Education for Health*. 2001; 14(2):182–197. [PubMed: 14742017]
- Kenya AIDS Indicator Survey (KAIS). Ministry of Health; Kenya: 2007.
- Lantz PM, Viruell-Fuentes E, Israel BA, Softley D, Guzman R. Can communities and academia work together on public health research? Evaluation results from a community-based participatory research partnership in Detroit. *Journal of Urban Health*. 2001; 78(3):495–507. [PubMed: 11564852]
- LaVeaux D, Christopher S. Contextualizing CBPR: Key principles of CBPR meet the Indigenous research context. *Pimatisiwin*. 2009; 7(1):1–16. [PubMed: 20150951]
- Lesser J, Oscos-Sanchez MA. Community academic research partnerships with vulnerable populations. *Annual Review of Nursing Research*. 2007; 25:317–337.
- Luginaah I, Elkins D, Maticka-Tyndale E, Landry T, Mathui M. Challenges of a pandemic: HIV/AIDS-related problems affecting Kenyan widows. *Social Science & Medicine*. 2005; 60(6):1219–1228. [PubMed: 15626519]
- Marcus MT, Walker T, Swint JM, Smith BP, Brown C, Busen N, et al. Community-based participatory research to prevent substance abuse and HIV/AIDS in African-American adolescents. *Journal of Interprofessional Care*. 2004; 18(4):347–359. [PubMed: 15801550]
- Miller RL, Shinn M. Learning from communities: Overcoming difficulties in dissemination of prevention and promotion efforts. *American Journal of Community Psychology*. 2005; 35(3/4):169–183. [PubMed: 15909793]
- Minkler M. Ethical challenges for the “outside” researcher in community-based participatory research. *Health Education and Behavior*. 2004; 31(6):684–697. [PubMed: 15539542]
- Molyneux S, Kamuya D, Marsh V. Community members employed on research projects face crucial, often under-recognized, ethical dilemmas. *American Journal of Bioethics*. 2010; 10(3):24–26. [PubMed: 20229411]
- Nyden PW, Wiewel W. Collaborative research: Harnessing the tensions between researcher and practitioner. *American Sociologist*. 1992; 24(4):43–55.
- O’Loughlin J, Renaud L, Richard L, Sanchez Gomez L, Paradis G. Correlates of the sustainability of community-based heart health promotion interventions. *Preventive Medicine*. 1998; 27(5):702–712. [PubMed: 9808802]
- Puffer ES, Meade C, Drabkin A, Broverman SA, Odhiambo RO, Sikkema KJ. Psychosocial correlates of HIV risk behavior among youth in rural Kenya. *AIDS and Behavior*. 2011; 15:1264–1274. [PubMed: 20945157]
- Rhodes SD, Hergenrather KC, Wilkin A, Alegria-Orgeta J, Montano J. Preventing HIV infection among young immigrant Latino men: Results from focus groups using community-based participatory research. *Journal of the National Medical Association*. 2006; 98(4):564–573. [PubMed: 16623070]
- Rhodes SD, Malow RM, Jolly C. Community-based participatory research: A new and not-so-new approach to HIV/AIDS prevention, care, and treatment. *AIDS Education and Prevention*. 2010; 22:173–183. [PubMed: 20528127]
- Ross LF, Loup A, Nelson RM, Botkin JR, Kost R, Smith GR, Gehlert S. The challenges of collaboration for academic and community partners in a research partnership: Points to consider. *Journal of Empirical Research on Human Ethics*. 2010; 5(1):19–31.
- Silka L, Cleghorn GD, Grullón M, Tellez T. Creating community-based participatory research in a diverse community: A case study. *Journal of Empirical Research on Human Research Ethics*. 2008; 3(2):5–16. [PubMed: 19385742]
- Tervalon M, Murray-Garcia J. Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved*. 1998; 9(2):117–125. [PubMed: 10073197]

- Varcoe, C.; Brown, H.; Calam, B.; Buchanan, M.; Newman, V. Capacity building is a two-way street: Learning from doing research in Aboriginal communities. In: Creese, G.; Frisby, W., editors. *Feminist community research: Negotiating contested relationships*. UBC Press; Vancouver, BC: 2011.
- Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. *American Journal of Public Health*. 2010; 100(Suppl. 1):S40–46. [PubMed: 20147663]
- Williams MV, Palar K, Derose KP. Congregation-based programs to address HIV/AIDS: Elements of successful implementation. *Journal of Urban Health*. 2011; 88(3):517–532. [PubMed: 21331749]
- Woman’s Institute for Secondary Education and Research (WISER). *Investing in Health and Education*. 2007. Available online at <http://www.wisergirls.org>



TABLE 1

## Characteristics of Community Advisory Committee Members

Sector	Gender	Age	Education Level <sup>a</sup>	Role(s) in Project <sup>b</sup>
Education	F	33	Post-secondary	CAC Chairwoman; Facilitator
Education	M	29	Post-secondary	CAC Secretary; Facilitator
Small business (clothing)	F	35	Secondary	CAC Assistant Secretary; Enumerator
Fishing / CBO member	M	39	University; Anthropology	Enumerator Team Leader; Expansion Leader
Education / Politics / CBO leader (HIV prevention for fishermen)	M	31	Post-secondary	Intervention Research Coordinator
Local government	M	65	Secondary	Church Leader Logistics Coordinator
Small business (catering)	F	24	Post-secondary (1)	Enumerator
Health (nursing)	M	38	Post-secondary	Enumerator
Education / School-based HIV education	M	43	Post-secondary	Logistics
Local government (Chief) / Small business (hardware)	M	54	Secondary	Facilitator
Homemaking	F	23	Secondary	Facilitator
Health CBO leader (PLWHA)	M	47	Secondary	Logistics
Small business (clothing)	F	29	Secondary	Logistics: Attendance Coordinator
Religion / Education	M	45	Post-secondary	Church leader facilitator
Religion / CBO leader (orphans / PLWHA)	M	59	Secondary (2)	Lead Facilitator for church leaders
Religion / Education	F	43	Post-secondary	Church leader facilitator
Homemaking	F	23	Secondary	Enumerator
Citizen	F	24	Secondary	Enumerator
Health (VCT)	M	33	Secondary	Enumerator
CBO leader (youth organization)	M		Secondary	CAC Member (other full-time employment)

M = Male. F = Female. CBO = Community-Based Organization. VCT = Voluntary counseling and testing. CAC = Community Advisory Committee. PLWHA = People living with HIV / AIDS. Notes.

<sup>a</sup>In Education Level, Secondary is equivalent to 4-year high school in the U. S.-based system. Post-secondary education is schooling after 4 years of secondary; most members completed 4 years of secondary and 2 years of post-secondary; exceptions are specified with the number of years completed in parentheses.

<sup>b</sup>Facilitators led intervention sessions. Intervention Research Coordinator collected process data, e.g., fidelity measures. Church leader facilitators led the discussion groups for church leaders, a separate component of the READY intervention. Logistics staff completed logistical tasks, such as materials preparation and scheduling. Enumerators administered surveys.