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Community Members as Recruiters of Human Subjects: Ethical Considerations

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Abstract

Few studies have considered in detail the ethical issues surrounding research in which investigators ask community members to engage in research subject recruitment within their own communities. Peer-driven recruitment (PDR) and its variants are useful for accessing and including certain populations in research, but also have the potential to undermine the ethical and scientific integrity of community-based research. This paper examines the ethical implications of utilizing community members as recruiters of human subjects in the context of PDR, as well as the authors' experience with a variant of PDR in a research project in South Africa. The importance of situating PDR in a comprehensive community engagement process that is responsive to the constraints of science and local needs and interests is emphasized. The paper will have relevance to bioethicists, health researchers, and research regulators concerned about the appropriate use of peer-driven recruitment strategies in health research.

Keywords

participatory research; peer-driven research; recruitment ethics

It is not unusual for health researchers to recruit human subjects using local intermediaries, that is, individuals who are themselves members of the population, community, or group in which the research is being conducted. Indeed, recent excitement over the “vast” and “untapped” research potential in India, Latin America, and other regions (Borfitz 2008; Lype 2004) may well fuel interest in this avenue of human subjects recruitment. In a best-case scenario, the utilization of local intermediaries for research recruiting purposes can be advantageous for all involved. For the intermediaries, the recruiting role may provide an opportunity for gainful employment, developing useful skills, and promoting self-worth. For researchers, the use of local intermediaries can enhance access to prospective research subjects, result in recruiting processes and materials that are reflective of local conditions, needs, and cultural norms, and promote research participation and capacity building within

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the research setting. For prospective research subjects, in turn, the opportunity to discuss a research study with local (as opposed to externally introduced or “outside”) recruiters may result in a more comfortable, interactive, and comprehensible informed consent process.

The distinctive nature of locally mediated recruitment also presents ethical challenges, however. These include the potential for researchers to exploit local recruiters through unfair employment practices, for recruiters to exploit the trust of their peers in their efforts to meet recruitment quotas, and for subject privacy and confidentiality to be more easily and egregiously violated. Here, we outline and discuss the ethics of utilizing community members as recruiters of human subjects for health research. We begin by considering the ethics of “peer-driven recruitment” (PDR), a methodology that has gained increasing traction in the health sciences in the past 5–10 years. We then discuss a variant of PDR that we utilized in a health research project in South Africa, where, among other factors, the incremental nature of empirical science and the level of personal and social need in the community may affect how community members experience the research recruitment process. The paper compares PDR and our variant of it in order to highlight how interconnected the ethics of this recruitment strategy may be with different levels of recruiter/subject proximity. Specifically, we argue that the physical, social, and cultural proximity of research staff to the community under study and to prospective research subjects may affect the ethical design and conduct of community-based research in both positive and negative ways. Examples of these proximity-linked ethical benefits and potential problems are illustrated with firsthand testimonies from a team of community research staff. We highlight the similarities and differences between PDR and our variant of it, including the extent to which we embedded our version of PDR in an extended community engagement process. We conclude with a summary of the potential linkages between recruiter/subject proximity and the ethical design and conduct of research, and the need for further research and discussion of these linkages in the research ethics literature.

Background

Community-based research typically includes many more activities and phases than just subject recruitment. These span study conception and design, funding, and the obtaining of approval to conduct the research at multiple levels; developing the research infrastructure (including the hiring and training of research staff); data collection, processing, and analysis; and, finally, results dissemination, translation, and application. Recent literature and research guidelines have emphasized the need for community engagement across these multiple activities and phases (Tindana et al. 2007; UNAIDS 2007) While there is no one universally accepted definition of “community engagement,” it is often held to be the process of working collaboratively with relevant partners who share common health interests and goals (Tindana et al. 2007). Concerns about the ethical and scientific integrity of community-based research have driven many of the calls for community engagement. For example, Guidance Point 2 in the 2007 UNAIDS document on ethical considerations in biomedical HIV (human immunodeficiency virus) prevention trials emphasizes the importance of community involvement and meaningful participation to help “ensure the ethical and scientific quality and outcome of proposed research, its relevance to the affected community, and its acceptance by the affected community” (UNAIDS 2007, 10). UNAIDS has also published the Good Participatory Practice Guidelines for Biomedical HIV Prevention Trials, which includes a call for effective community engagement during the “entire life-cycle” of a biomedical HIV prevention trial, and beyond (UNAIDS 2007, 8). While these guidelines are reflective of the particular concerns surrounding the conduct of HIV prevention trials in the developing world, the need for community engagement throughout the research process has been widely advocated for in other health and disease contexts, in both the developed and developing world. These calls are reflective of the growing shift toward community engagement in research for both ethical and scientific reasons.

Within the broad framework of community engagement, subject recruitment presents one opportunity for involving community members in research. In turn, peer-driven recruitment (also sometimes called network sampling or respondent-driven recruitment) is a particular strategy for recruiting research subjects with the assistance of community members (Abdul-Quader et al. 2006; Bianchi et al. 2003; Tiffany 2006; Broadhead et al. 2006; Sergeyev et al. 1999; Heckathorn 1997; Griffiths et al. 1993).

PDR and its variants have been utilized in combination with other community engagement activities in the research life cycle (Mosavel et al. 2005) as well as in apparent isolation (Broadhead et al. 2006). Developed in the United States and now increasingly utilized here and in other parts of the world, PDR works through the tapping of a community member's social network. Typically, PDR involves identification of a first wave of research subjects who are asked to identify and approach other community members with the option of participating in research. Assuming they are willing, these other community members can then in turn be mobilized as peer recruiters. This process of chain recruitment continues until the target sample size for the research has been reached. While approaches differ, the tasks that peer recruiters are normally asked to carry out include seeking out potential research subjects, providing them with verbal and/or written information about the research (including an informed consent document, if applicable), answering questions about the research, and, in some cases, obtaining consent.

Given these various roles, PDR can be seen as serving both ethical and strictly utilitarian goals. On the utilitarian side, PDR is a strategy whereby the “insider” status and knowledge of peer recruiters can be usefully tapped in an effort to overcome the difficulties that investigators might otherwise face in recruiting and conducting research with individuals or groups who have potentially tangible reasons to mistrust and even avoid outsiders, such as illegal workers, injection drug users, and homeless individuals. On the ethical side, PDR has been viewed as morally positive because it facilitates access to and involvement in research of such historically neglected research populations as injection drug users and homeless individuals (Bianchi et al. 2003; Tiffany 2006). PDR has also been viewed as reflective of a community engagement philosophy insofar as it seeks to mobilize community members to play an active part in the research recruitment process—a step that potentially could be extended to other activities and phases in the research life cycle (Bianchi et al. 2003; Tiffany 2006).

PDR raises the prospect of a number of ethical concerns. First, in its utilitarian garb, PDR can be—and has been—used in isolation from any more comprehensive community engagement approach. Isolated use of PDR can devalue or undermine the potential for community members to play a far more active and meaningful role in the research production process than allowed for in the narrowly defined role of peer recruitment.[1] Second, there are questions surrounding the ethical and scientific integrity of PDR's reliance on peer recruiters. This form of “insider” recruitment raises the possibility that some prospective research subjects, or even whole subgroups of subjects, may be excluded from the research as a result of biases on the part of peer recruiters in terms of whom they consider members of their social networks. The concept of using successive waves of peer recruiters to tap multiple overlapping social networks is intended as a corrective to these potential sampling biases; however, as with most sampling techniques that work through subject referral, the problem of bias in this form of sampling is hard to detect and eliminate

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[1] We thank an anonymous *AJOB* reviewer for pointing out this salient limitation of PDR.

(Heckathorn 1997; Atkinson and Flint 2001). Third and relatedly, the nature of peer recruitment and its preferred use in relatively small and intimate communities magnifies the need for ensuring subject privacy and confidentiality, an issue that has been raised (Margolis 2000) but not much discussed in the PDR literature (Broadhead et al. 2006; Tiffany 2006). Fourth and perhaps most seriously, PDR invites the potential for exploitation of peer recruiters and/or their social networks, particularly in cases where peer recruiters are compensated on a per-capita basis for successfully referring or recruiting their peers into the research. In fact, recent data from PDR researchers suggests that "the more participants are paid for recruiting, the more persons they will refer," and that, within this utilitarian framework, per-capita compensation is among the most instrumentally effective model for peer recruitment (Broadhead et al. 2006). To address the possibility that per-capita compensation may encourage "super-recruiting" in which peer recruiters may resort to overzealous and potentially coercive methods in their referral or recruitment efforts, PDR researchers advocate imposing quotas on the number of subjects that index cases can refer or recruit (Tiffany 2006, i121). Notably, a number of institutional review boards (IRBs) and research institutions have considered the issue of compensation in PDR, but have not necessarily distinguished per-capita from other forms of compensation (Johns Hopkins IRB 2006; University of Toronto 2003). By contrast, some ethicists have recognized the risks inherent in per-capita compensation models for subject recruitment, and discourage their use in favor of "block" compensation models (Christensen and Orlowski 2005).

In sum, PDR is a method for sampling and recruiting research subjects that operates through the mechanism of insider knowledge and network utilization. It can be used in combination with or in isolation from comprehensive community engagement strategies. Its potential benefits include providing access to difficult-to-reach populations, promoting the inclusion of these populations in research, and involving community members directly in the conduct of research. The ethical concerns linkable to PDR include its potential to devalue the full role of community members in research; to heighten the risk of sampling biases and breaches in subject privacy and confidentiality; and to potentially encourage exploitation and coercion in subject recruitment. Next, we consider the approach we took in mobilizing community members in a South African study recruitment process, and how this approach compares to PDR in terms of its design, implementation, and ethical implications.

A Variant of PDR in a South African Health Project

Why Recruit With Community Members?

We used a variant of PDR in research we conducted in a multiethnic, resource-poor community of approximately 75,000 people near Cape Town, South Africa. The research was focused on cervical cancer, a highly preventable disease that claims the lives of a quarter of a million women worldwide every year. In South Africa, the age-standardized mortality rates for cervical cancer have been estimated to range from 3.6 for metropolitan Whites to 30.2 for non-metropolitan Coloureds and 25.7 for metropolitan Blacks, suggesting that Coloureds and Blacks in South Africa are at a disproportionately high risk of dying from cervical cancer (Bailie et al. 1996). The primary goal of our research was to find out how much women in the community knew about cervical cancer, whether they would be willing to get screened for the disease if they had not already done so, and what personal, social, and other barriers they perceived as standing in the way of getting screened. The decision was taken early on in the conception of the research study to employ community members to assist with study recruitment, data collection and analysis, and local data dissemination. This decision was a logical extension of a community consultation process that we viewed as critical given the larger ethical and moral issues relevant to our research and North/South research in general (Simon, Mosavel, and van Stade 2007).

Community consultation helps foster mutual trust, support, and partnership in research (Dickert and Sugarman 2005), which is especially important in the context of under-served and under-researched communities. The community in South Africa was created under apartheid, was affected by multiple social and health problems, and was comparatively new to the complexities of hosting externally sponsored research. These factors, among others, made the community potentially vulnerable to exploitation, on the one hand, and mistrustful of outside intervention, on the other. At the same time, our research was conceived as a 3-year project development and scientific data collection effort, a timeline that contrasted sharply with the resource-poor nature of this community and its many immediate health and social needs (Simon and Mosavel 2008).

In an attempt to offset some of these issues and constraints, an intensive community consultation process was implemented and designed. Input and advice on the appropriateness of the research question and design, goals, and methods of the research were obtained from many different sectors of the community, including church leaders, women and youth groups, community health workers, clinic physicians, school boards, local healers, and laypeople. (Mosavel et al. 2005). This process included discussion as to the need for research on cervical cancer, given the prevalence of other health and social problems and needs in the community. Among the different stakeholders consulted, there was widespread agreement that cancer was a major concern, and that cervical cancer, among other reproductive health issues, was increasingly an issue for women (Mosavel et al. 2005). A survey that we more recently conducted of women attending a cancer screening event in the community provides further evidence that cervical cancer is a health priority for many in this community, despite limited knowledge of the disease and its prevention (Mosavel et al. 2009). The decision to employ community members as research recruiters was aimed, at one level, to formalize and extend the community engagement process to include active participation of community members in the conduct of the research. At a related level, it was intended to demonstrate our commitment to partner with the community and involve it in the research, wherever possible.

Selection, Background, and Training of Staff

The employment of community members in research, particularly in settings affected by poverty and unemployment, is in itself a sensitive ethical issue. Like other modestly funded health studies, our research budget allowed only for the temporary employment of a small team of part-time research staff. To find these staff members, we asked leaders in different sectors of the community (such as the primary health care and school systems) to recommend individuals who possessed the basic qualifications necessary for our research (literacy, bilingualism in English and Afrikaans or English and Xhosa, and flexible hours). We also solicited advice from community members and local university researchers regarding an appropriate compensation model for the staff.

Approximately 10 individuals were recommended to us and subsequently interviewed. The outcome of this process was a team of seven research staff selected on the basis of availability, community recommendation, and the specific needs of the project. All the staff members were female, in order to promote rapport with our research participants, who would also be female. The staff members were high school graduates and literate, relatively young (between the ages of 22 and 35 years), and collectively fluent in the three languages spoken in the community. All but one of the seven staff members lived directly in the community; this staff member lived in a nearby community. All the staff members were financially compensated at a weekly block rate that was calculated using the recommendations we had received in this regard. Staff were also reimbursed for project-related travel, and provided with food and refreshments throughout all their training phases. Certificates of achievement were drawn up, signed by the study principal investigators (PIs), and presented to staff members at the end of the research. The PIs and a study coordinator worked with several staff members to find them employment opportunities after the research had ended.

No one on the research team had prior experience conducting research. Therefore, our training of the research team included a 2-week intensive on-site workshop and a number of “refresher” sessions covering a range of topics, including the importance of informed consent, the need to protect subject privacy and confidentiality, data quality and integrity issues, managing challenges in recruitment, and similar topics. Staff members were closely monitored for progress during training and were provided with group-and individual-level feedback. Mock exercises and pilot-study research provided a context for staff members to test out their newfound ethics knowledge and research skills, and for the study PIs to monitor and provide staff members with additional feedback. Training of staff continued on a more informal basis during the actual research, through weekly debriefing and research review sessions with either the study PIs or project coordinator.

Staff Input and Education of the Investigators

Our interactions with research staff were mutually educational from the outset. While we trained staff in data collection, subject protection, and other issues, staff members educated us in the norms and values of their community, potential barriers to the research such as low literacy, and other issues. Staff members also helped tailor the study's recruitment plan, consent documents and process, and data collection and analysis in ways that reflected their local knowledge and expertise. For example, our original plan was to interview women at a central location in the community. Questions and comments by research staff suggested that many women would find this plan unappealing, given their home and child-care duties and the visibility of traveling to a central location for a research study. Staff members recommended approaching and interviewing women in their homes instead, for the sake of their convenience and privacy.

Staff members also played a key role in shaping the informed consent process for the research. For example, staff members were asked to review the consent document that we drafted in the United States, comment on its appropriateness, and translate it into understandable Afrikaans and Xhosa. To this end, a series of workshops was held in which staff members considered the linguistic, cultural, and social appropriateness of the consent document, and the study PIs reflected on the formally (IRB) required content and format of the document. The workshopped document was then submitted to our U.S. institution's IRB for approval, as well as to local oversight authorities in South Africa for their approval.

Problems and Challenges

The research faced a number of problems and challenges associated with recruitment. The sampling technique for the research was random and meant that staff had to locate and approach a relatively small ($n = 450$) number of prospective subjects in a poorly mapped community of over 70,000. Approaching prospective research subjects in their homes proved more difficult than was anticipated. Women were often not available on the days and times staff members had scheduled to meet with them, or were too distracted by domestic chores to allow staff members to properly conduct the informed consent process. Delays in approaching and consenting women were frequent, and the overall recruitment plan was somewhat impacted as a result.

Staff members were asked at weekly debriefing sessions, held throughout the recruitment and research phases, to provide feedback on the informed consent process. They reported early on that, despite their best efforts, the process was challenging and some prospective research subjects appeared to be having difficulties comprehending the research. Comments from staff included:

> Mary: “It was challenging in terms of their understanding. They had a lot of questions that had nothing to do with the study.”
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> Nontande: “It was not easy because you first have to find out what the participant's level of living is. You have to come to their level to set up the atmosphere. Although you explain to them what the study was all about, they had their own expectations.”
>
> Lila: “Some of my cases were very comfortable, pleasant, and funny and others simply don't understand.… I've had a couple of women who can't read or write, in that case I had to explain each question several time for them to understand and write their answers down. When I go through the consent forms they usually agree with everything and say that they understand.”

Another challenge that surfaced more gradually was the emotional or psychological impact of the recruitment and research process on staff members. This affected all the staff, but especially younger staff members. Staff concern and anxiety for the circumstances of some of the women they approached appeared to be the key issue. Three examples follow, told from the perspective of research staff:

> Wendy: “I got very concerned about this woman being so skinny. You can tell that she is sick. You don't even have to ask her. I'm worried about the situation she is living under. She had some bad bruises… the face is so wrong. I didn't think that I can cope.”
>
> Marzanne: “I observed that she don't have any friends to share her problems with. She seems depressed and nervous. I think that she must seek professional help because she is neglecting herself and her house. She takes very good care of her children and she provides for them no matter her circumstances she's in. She is a very beautiful person, but just needs guidance and professional help.… Sometimes, from what I've observed, everything is too much for her.… She needs help A.S.A.P. so that her life can be more easy. Yes!! She did smile during the interview, but it was only when she had to. The face I see of her is the face of a sad woman who reaches out for help, but seldom gets it.”
>
> Nontande: “It wasn't easy because I met different people having different problems. So, when we talk about personal lives, some of their problems were touching me, and some of them are very sad or bad, and I couldn't even sleep at first and I think about it but I take it—I've tried not to take it personally.”

Since these narratives evidence a fair amount of insight into these women and their circumstances, it is important to add here that staff members did not personally know any of the women they interacted with during the recruitment process. In fact, because we felt that personally knowing a prospective research subject had the potential to influence the informed consent process in unpredictable ways, the decision was taken at the outset of the research to ensure that research staff members were not paired with prospective research subjects whom they knew. This decision was carried out throughout the recruitment process through a careful weekly review of the names of prospective subjects that each staff member was responsible for approaching. Few pairings were to our knowledge encountered; in those cases, the subject would be delegated to another staff member.

Staff members showed signs of emotional stress and fatigue as a result of engaging in the sort of interactions just described. They used words like “helpless” and “sad” to describe their own reactions to these interactions. One staff member reported that she was beginning to have problems sleeping at night as a result of her research experiences.

Responses from the Project Leadership

We took steps in an effort to address the problems and challenges just outlined. To address the issue of scheduling delays, we provided staff with prepaid cell-phone minutes so that they could call prospective research subjects before setting out to meet them (subjects were called only if they had previously agreed to give out their cell-phone numbers). Because many people in this community carry cell phones, this simple strategy proved to be very effective in minimizing delays during recruitment.

To address some of the challenges that staff members reported experiencing with the study's informed consent process, we developed a relatively simple pre-consent quiz along the lines of what other researchers have more recently developed (Molyneux et al. 2007; Rounsaville et al. 2008). The quiz was aimed at allowing staff members to more systematically identify and respond to gaps in subject understanding of the research. It consisted of five questions (see Table 1) that were jointly developed with staff. Staff members were asked to administer the survey *after* their initial discussion of the research with eligible participants, but b*efore* women were asked to make a decision about participating in the research. Staff members were trained on how to use the quiz and were asked to provide feedback on its use following implementation. On the whole, staff members reported gaining greater control over the informed consent process and improved subject comprehension as a result of using the quiz.

We took a number of steps to address the emotional and psychological impact of the research on staff. First, we extended our weekly debriefing sessions in order to discuss staff members' field experiences and suggest ways in which these experiences might be improved, for example, through encouraging staff to refer women to appropriate local support services that we researched and included in a list that staff members could provide to women. This list replaced an earlier, less tailored version. Second, we hired a South African psychologist with extensive experience working in local communities to meet weekly with staff members. Among other coping strategies, the psychologist encouraged staff members to keep a research diary of their field experiences, a step that staff members reported finding very useful. Finally, we provided additional training for staff members aimed at reinforcing the importance of respect for prospective research subjects, including respect for subject privacy and personal confession.

While the exact impact of these steps could not be measured, staff members reported that they helped incrementally in their efforts to cope with the emotional effects of the research. None of the staff members left the project over the 12-month recruitment and research phase. Only one staff member left the project over the 3-year lifecycle of the research.

Discussion

Ethical Similarities and Differences

The approach taken to subject recruitment in our project in South Africa shared a number of contextual characteristics and underlying goals with PDR. As is the case in most research utilizing PDR, our research was conducted in a relatively marginal, under-researched, and underserved population, albeit one not defined by a single prevalent behavior such as drug use or homelessness. For us, utilizing community members in the recruitment process helped practicably address the challenge of accessing this population and overcoming potential trust barriers, particularly at the level of actual subject recruitment. Notably, our hiring and training of community members as research staff was part of a larger effort to engage the community in the reflexive design and conduct of the research, as far as was possible. Our approach made it possible for a number of community members to be actively involved in the conduct of the research beyond just recruitment, and to benefit accordingly through the income, training, and skill-building accompanying this extended opportunity. Finally, our variant of PDR capitalized on the “insider knowledge” of community members in much the same way that PDR does, but with an emphasis on incorporating this knowledge into the design of a contextually sensitive set of recruitment and informed consent procedures and, more broadly, into an ongoing dialogue and process of reflection about the research.

PDR and the variant we used were different in a number of ethically consequential ways. For one, PDR studies tend to hire a significantly greater number of community members than was possible in our study. In fact, PDR depends on the hiring of a relatively large number of recruiters as a result of social networks being exhausted through the recruitment process and new ones needing to be identified and tapped. The benefits of being hired by researchers, including income, skill-building, and related benefits, may be that much more widely dispersed through the PDR research population as a result. On the other hand, because of the need to utilize multiple waves of recruiters, an individual PDR recruiter may only be with a project for days or a few weeks at a time. In our approach, a small cadre of community members remained with the project for several years, including over the 12-month study recruitment period. These staff participated in a broad range of research activities and built up a diverse research skill set as a result. This longer term relationship may also have allowed for the development of stronger mutual trust and rapport between the project leadership and research staff, and among research staff members themselves.

Another key difference between PDR and our approach is that recruiters in PDR tend to personally know the prospective research subject, while in our research, as a result of the preventative steps we took, they did not. Similarly, recruiters in PDR frequently are or have been research subjects themselves, while in our research this was not the case. On the one hand, these shared attributes in PDR have the potential to enhance the informed consent and overall recruitment process, for example, by allowing the PDR recruiter to speak firsthand to the experience of participating in the research study as well as to the experience of having been a fellow injection drug user, homeless person, or medically uninsured factory worker, as the case may be. Such firsthand knowledge may be highly useful in promoting a well-informed decision about the option to participate in the research. On the other hand, one can also easily imagine a situation in which recruiters seek to promote participation in a research project by claiming that they benefited greatly from the research and/or were not significantly harmed in any way, and that the prospective research subject could therefore expect a similar outcome. In our view, this would be an inappropriate claim for a peer recruiter to make. Different individuals' experiences of a health problem and/or of participating in research are likely to be highly variable, and to be interpreted with a great deal of subjectivity. A recruiter's personal experience is not, therefore, an acceptable framework for conveying the risks and/or benefits of participating in research.

Our study sought to avoid this and other potentially inappropriate influences on the informed consent process by employing recruiters who were not research subjects themselves and who were not personally connected with the study's prospective research subjects. At the same time, this more distal aspect of our recruitment process may account in part for some of the challenges that arose in our research. Certainly, some of the events that caught our recruiters off guard—such as the challenge of reaching women in their homes—would likely be better anticipated or avoided by recruiters with more intimate knowledge of their peers and when and where they could be found. Moreover, because our staff members were not research subjects themselves nor immediate peers of the women they approached, they may well have been less prepared for some of their experiences in women's homes. At the same time, the recruiters in our study were no strangers to the problems in their community. As their firsthand observations so profoundly illustrate, they displayed great awareness and empathy for the signs of poverty, abuse, and violence they encountered.

Recruiter/Subject Proximity: One Factor Among Others

Ethical dilemmas have the potential to arise in all research recruitment approaches, regardless of recruiter/subject proximity. Similarly, there may be considerable variation in ethical implication within PDR itself depending on the approach taken. For example, the choice of how peer recruiters are compensated may play a greater role in affecting the ethical outcomes of PDR than the "peer-driven" element of the approach in and of itself. Yet, per-capita compensation of recruiters may be more likely to compromise the integrity of an informed consent process where recruiter/subject proximity is high, that is, where social knowledge, ties, and relationships figure prominently into the recruitment process. Attempts at coercion may be much more likely and effective in situations where overmotivated recruiters are able and willing to exploit their insider knowledge and social ties and relationships. Similarly, recruiter/subject proximity may play a role in determining how the recruitment process will affect the recruiters themselves and, indirectly, the progress and quality of the research. In the case of our research in South Africa, the obvious emotional distress evidenced by the research team may have been linked to their sharing of a number of characteristics with the women whom they approached, including communal space, gender, and, in some cases, the shared experience of domestic violence and abuse. As Ann Oakley has observed, the relationship between female researchers and research participants is often a powerful and evocative one (Oakley 1981). While the moral imagination may allow even the most culturally distant outsider to feel empathy and compassion in the face of human suffering, as often happens when foreign students are introduced to developing-world research settings,[2] being part of the same community as one's research subjects and sharing certain characteristics with them such as gender may significantly heighten that sense of empathy, compassion, and concern. The personal experience of carrying out scientific research in one's own community may also involve a heightened sense of moral duty. Part of the helplessness and frustration that our research staff experienced may have resulted from this sense of duty and the barriers standing in the way of acting on this duty, including the research process itself—its incremental nature, its insistence on scientific objectivity, and its inability to offer up immediate solutions to address the obvious and pressing needs of community peers, in particular.

Recommendations for Future Research

The potential linkages we have explored between recruiter/subject proximity and the ethics of community-based research need further investigation and discussion. In particular, research may be needed on the ethical implications of different degrees of experiential and knowledge-based concordance between recruiters and prospective research subjects. Studies comparing informed consent processes and outcomes in research utilizing inside versus outside recruiters may well provide valuable insights in this respect. An ongoing PDR study could provide a convenient laboratory for this type of study. "Outside" recruiters could be trained and asked to recruit subjects in exactly the same way as peer recruiters, and then observed and interviewed with the goal of comparing their recruitment experience to that of peer recruiters. Similarly, retrospective studies could be conducted to better understand the potential for recruiter stress and lack of coping, with recruiter/subject proximity as a variable of interest. Additionally, there is the need for qualitative research on how community partners, stakeholders, and prospective research subjects may (differently) perceive peer

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[2] Again, we are grateful to an anonymous reviewer for this insightful point about the connectivity of the "moral imagination" in research.

versus outside recruiters; there are questions of researcher representation and identity; and there are the ethical issues that potentially are linked to recruiter/subject proximity. These and other studies would be useful also for exploring some of the ethical issues that we were not able to investigate for lack of data, such as the potential for recruiter/subject proximity to magnify the risk of compromising confidentiality and privacy, a link that has been explored from a legal perspective (Margolis 2000), but not empirically.

Conclusion

Few, if any, studies have considered in any detail the ethical issues surrounding peer-driven recruitment and its variants. These approaches have the potential to result in tailored improvements in recruitment strategies, informed consent processes and materials, and other components of the research, as this paper has tried to illustrate. At the same time, these benefits may be offset by problems such as the potential for exploitation of recruiter proximity; overestimation of the accuracy of insider knowledge; the introduction of sampling bias; the heightened risk for coercion; and the potential for profound coping difficulties among inside recruiters. A comprehensive community engagement philosophy may be essential in the effort to maintain a healthy balance between the potential ethical benefits and burdens of peer-driven recruitment. Many community engagement models advocate for the participation of community members at most or even all stages of the research life cycle, with the aim of fostering mutual understanding and trust, building local capacity, and avoiding unbalanced and exploitative relationships. The use of PDR in a strictly utilitarian form, divorced from any effort to involve community members in other phases of the research, may be counterproductive to this larger effort. At the same time, as our work in South Africa illustrates, a community engagement process may not be sufficient in itself to prevent problems arising in peer recruitment. Other complementary strategies may be required, including proactive education and training with communities and research staff, aimed at identifying and anticipating the problems that may emerge where recruiter/subject proximity is coupled with the constraints of science, on the one hand, and the up-close witnessing of suffering and need, on the other.

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Table 1

Items in the consent assessment survey recommended by staff

Questions:	Potential problem areas
1. Can you tell me why you are interested in this research?	Misunderstanding of descriptive nature of research
2. Can you tell me what this research is about?	Misunderstanding goals of research
3. Can you tell me what you are being asked to do for this research?	Misunderstanding research procedures
4. People who are asked to be in research have certain rights. Can you tell me what your rights are?	Lacking awareness of right not to participate, right to end participation
5. Is there anything about this research that you are worried or unclear about?	Failing to address concerns about or gaps in understanding of the research