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CLINICAL CASE

Setting the Agenda for Community-Based Participatory Research

Commentary by Jessie Kimbrough-Sugick, MD, MPH, Jessica Holzer, MA, and Eric B. Bass, MD, MPH

Dr. Peck, an academic researcher, is looking into the correlation between teen suicides and peer bullying around the country. He goes to Frederick Heights because that community has had two suicides in 3 years, a high occurrence for a small community. His colleague, a psychiatrist, sees several youths from the community, and these patients have reported disturbing patterns of bullying. A Frederick Heights community group has established positive partnerships with other researchers from the local university, and Dr. Peck feels it is best to meet with this group before proceeding with the study. Dr. Peck speaks with the community group's board of directors to gauge their interest in a study that explores interventions to prevent bullying.

Most of the board members are part of the congregation of a conservative church. In the meeting, members state that the two boys who committed suicide were homosexual and that being gay is wrong. They say the research is neither important nor relevant in their community in spite of the statistical data. The board chairperson attempts to open the members' minds to the research idea by saying, "I know this is a difficult subject to talk about, but it doesn't mean those with 'alternative lifestyles' who live in our community don't deserve our protection."

His words are drowned out by phrases like, "Not here they don't." One member says, "I think the board should be focused on bringing research to the community that looks at the positive effects of religion on teen vandalism. Because you know we started a Friday night Bible class for young adults about a year ago, and there has been less graffiti and loitering."

Commentary

This case highlights important ethical issues that may arise when researchers and community leaders who seek to engage in community-based participatory research (CBPR) discover they have conflicting values.

Conflicting researcher and community agendas can lead to ethical dilemmas that might be better understood using the principles of biomedical ethics. Those principles are respect for autonomy, beneficence, nonmaleficence, and justice [1]. Although primarily applied to individual interactions, such as those between a researcher and study participant, these principles should be applied to communities

as well. They may offer guidance to researchers approaching communities with the intent to engage in research on a sensitive topic.

Autonomy of the Community

In research, respect for the autonomy of individuals underpins the practice of informed consent, limiting the degree to which researchers and institutions can impose their own agendas on individuals, regardless of the potential benefit for those individuals [2]. An underlying assumption in CBPR is that the community has interests and agendas that deserve respect and deference from researchers [3]. This can be viewed as respect for the autonomy of the community, which lays the foundation for a genuine partnership between the researcher and the community.

In the case described above, Dr. Peck has come to the community with a research agenda in hand. His agenda is not that of the community, which leads to the conflict highlighted in the case. Respecting the community's autonomy—its right to pursue its own interests and values—demands developing a relationship with the community at an early stage [3, 4]. In this way, the community can exercise its autonomy in setting priorities for the partnership and the research in conjunction with the researcher. In this first phase, Dr. Peck should ask the community members about their needs and interests and how his proposed work might help meet those needs.

Conversely, Dr. Peck should ask himself, "Is my proposed research agenda driven by external factors (e.g., funding opportunities, personal interests, institutional priorities) that are controversial or not aligned with the community's agenda?" Dr. Peck assumes that his interest in understanding the causes of teen suicide so that no more teens will take their lives is shared by the group's board. He seems unaware of the complexity of his research interest and the controversy that surrounds it in the community.

Beneficence and Nonmaleficence in CBPR

While it is not expected that individual participants necessarily gain benefit from participation in traditional research [2], it is expected of CBPR that actions will be taken to improve or promote the health and well-being of community members [4]. In other words, CBPR should be beneficent—it should help the community [4]. Complementary to beneficence is nonmaleficence—do no harm—another fundamental principal in biomedical ethics [5]. Dr. Peck should ask himself, "Will my research bring benefit to the community, and is there risk of causing harm to the community or to the partnership?" If this conflict is not handled in a thoughtful manner, a study that shines more light on gay teenagers could harm rather than help those at risk. Unintended consequences may include mistrust and deterioration of the previously established partnerships between the community and other research entities. Moreover, without the support of the community, the research findings may be limited.

Social Justice in CBPR

The concept of social justice takes the form of communitarianism and egalitarianism in CBPR. The communitarian perspective argues for developing the obligations of the community to the individual and those of the individual to the community from principles that are pluralistic and derived from within the community, rather than from external sources [6]. Egalitarianism, on the other hand, is the view that individuals deserve equal treatment, especially in the case of essential goods, such as health care. The principles of egalitarianism are derived not from the community but from the more fundamental social acknowledgement that each of us wishes to be treated fairly. One principle of egalitarianism is that each individual has the maximum amount of liberty compatible with a similar allowance for others. A second principle is that inequalities in primary goods, such as health care, are tolerated only insofar as the system in which they exist benefits the whole and everyone has an equal opportunity to seek better status [6].

In this community, Dr. Peck has identified a troubling unfairness—gay teens are bullied to a greater degree than other teens. Suicides of gay teens have occurred recently, raising the prospect that increased bullying may be related to the increased occurrence of teen suicide. This is a public health and social justice issue that deserves attention. A researcher who sees such a troubling trend in a community reasonably feels a duty as a public health professional to address the problem.

The community's lack of interest in studying the relationship between teen suicides and bullying causes conflict between the board's communitarian view and Dr. Peck's egalitarian view. The board has expressed the values it believes are fundamental in this case, derived from the values of the community. Dr. Peck has expressed a more egalitarian view that especially bad treatment of a specific group—gay teens—merits investigation and amelioration.

The tension between the communitarian and egalitarian perspectives puts Dr. Peck in a difficult position. Does he work with the community on the issue of church outreach programs' effects on vandalism, delaying or potentially forgoing development of interventions that may save the lives of vulnerable teens? Does he separate himself from the community group and go his own way to address the teen suicides and bullying?

The risk of not investigating teen suicide is that a significant public health concern may go unaddressed and that vulnerable persons within the community may continue to suffer. Dr. Peck could establish a relationship with the community's board in the hope of convincing them of the ethical imperative to pursue social justice in their community. In the interim, however, his agenda would not be advanced and there would be no guarantees it ever would be addressed.

Practical Options for Addressing Ethical Concerns and Conflict in CBPR

To minimize conflict between community autonomy and the researcher's aim for community health and wellness promotion, Dr. Peck should have done more

preparation for his meeting with the community's board. At the very least, he needed to know what community stakeholders were represented on the board, in this case, primarily members of a conservative church who judged gays negatively. This knowledge might have enabled Dr. Peck to frame his research in terms of the generalizable consequences of bullying, suicide, and copycat suicides among adolescents—regardless of the impetus.

Seeking common ground and interests within the community could have led to a more satisfying experience and research partnership [2]. Dr. Peck should have identified and reached out to potential allies such as the board's chairperson and others in the community. Furthermore, he should have engaged the board's chairperson as a lead collaborator in the development of the research [7]. Bringing other community voices to the table [4], such as those personally affected by the suicide tragedies, might have lent substance and humanity to the discussion between Dr. Peck and the board. Finally, Dr. Peck might have reached out to public health officials, school boards, parent organizations, and town councilpersons to achieve community-wide understanding of the issue, build consensus, and identify strategies to address the public health problem.

All is not lost. Dr. Peck can still study teen suicide in Frederick Heights, despite the board's objections. He must, first and foremost, ensure good lines of communication between himself and the community's board [8, 9]. Good communication can form the basis for resolving or minimizing conflict, just as impaired communication can cause or aggravate conflict. He should seek counsel from respected colleagues and community leaders outside the board [10]. In the clinical setting, a hospital ethics committee is available for conflicts involving patient autonomy and provider intentions regarding beneficence and nonmaleficence [11]. In the CBPR setting, there may not be an equivalent ethics committee other than an institutional review board. However, seeking advice from colleagues in and out of this field of research, as well as nonresearchers related and unrelated to the town, might prove helpful in sorting out the complexities of the conflict and salvaging the research relationship.

Alternatively, Dr. Peck and the board may reach a point where they agree to disagree [10]. In that instance, Dr. Peck may pursue his research interests without the help of the board. If he establishes relationships with other entities or members of the community, Dr. Peck may form a different partnership.

Regardless of whether or not Dr. Peck can reach an agreement with the community's board, it will be important for him to apply the principles of virtue ethics to his CBPR experience [12]. In situations of conflict, the virtues of compassion, courage, honesty, and humility all have a role. Dr. Peck's compassion for the victims of bullying should be accompanied by courage in expressing his concerns. In doing so, he will need to be honest about his interests and abilities, while also being humble enough to recognize that he cannot solve the problem without help from people in the community.

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