

Ethics and Community-Based Participatory Research: Commentary on Minkler

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As always in her distinguished career, Meredith Minkler gives voice to those who could be the victims of our well-meaning but sometimes insensitive and potentially harmful professional practices, research, policies, programs, or services. That voice, always articulate and unflinching, if sometimes hoarse from crying out in the wilderness, makes us look more critically at our assumptions and methods. The wilderness in this case is the relatively uncharted territory of community-based participatory research (CBPR).¹

Ethical issues arise most predictably and wickedly when new technologies offer new choices of action where competing moralities, laws, and politics had attained something of an equilibrium or stalemate with the old technologically feasible choices. Thus have we grappled with the uneasy questions raised in recent years following the introduction of new potential actions and choices offered by the unraveling of the human genome, the discovery of the multitude of possible cellular forms that stem cells could be programmed to develop, and the advances in pharmaceutical therapies that could benefit people in populations and countries that cannot afford the costs associated with their development.

We are caught more off guard, however, when ethical issues arise within our zones of philosophical comfort and even smug self-righteousness. Such are some of the issues that Professor Minkler raises in relation to CBPR. This approach to research seemed to fit so comfortably into the philosophical commitments of health education to participatory approaches in community work, into our educational and behavioral science assumptions about participation in the learning process, into our social commitments to shared decision making and learning that we hardly anticipated an assault from ethical quarters. Resistance was not unexpected from those who doubted the methodological rigor of such research or questioned the objectivity of scientists who abandoned the arm's-length posture of positivist science or the unblinding of "subjects" of research in making them coresearchers. But ethical questions were the last we might have expected to face.

FIRST CHALLENGES: DEFINITION AND SCOPE

Even before we heard Professor Minkler's issues, we began to face some questions that might have been construed as ethical when grant programs began to entertain proposals that purported to be participatory research but that were, in fact, projects in which the

participation was as perfunctory as being consulted or at best asked for permission to conduct the study in their population. Was this an ethical issue or simply poor conceptualization and communication of definitions? Guidelines emerged from those early attempts to make the review of applications for funding of participatory research more rigorous.²

A related definitional issue arose when we found, in Canada at least, that the most extensive participatory research that could guide us in developing the guidelines for others was being done not in communities as Professor Minkler has used that term in “community-based participatory research” but in hospitals and other organizations where academic researchers were being called upon to help professional staff solve a problem. Among these examples of participatory research were university nursing faculty called upon by hospital staff nurses to help them document and study some of the working conditions that were causing staff attrition and recruitment problems. This has led some of us to prefer to use the more generic term *participatory research*, to encompass the full spectrum from “community based” to work with health policy makers and professionals as the form of town-gown relationship.³ Even within communities as Minkler has intended the term, she acknowledges a wide range of definitions “depending on the background and circumstances of the persons with whom the outside researchers spoke, with strong divides on the basis of religion, urban-suburban residence, level of assimilation, and gender.”

These first challenges would caution us to work hard on defining terms and validating and scoring proposals that purport to be participatory research, including their clarity of delineating communities and subcommunities.

SECOND CHALLENGES: SHARED RESPONSIBILITY AND GOVERNANCE

A second round of ethical challenges arises as the research partners come together to work out the division of labor and the sharing of responsibility. These might be referred to broadly as “rules of engagement” or governance of the research process. Minkler borrows the principles developed and articulated by Barbara Israel and her colleagues. These include one that insists that the community members and [conventionally defined] researchers engage “in a joint process to which each contribute equally.”⁴ The term *equally* here has produced much heartburn for community members and researchers alike, struggling to rise to the challenge of carrying their side of the bargain as it might be measured in hours of labor (for which community members often are unpaid), data collection (for which community members or researchers might suspect they are being exploited for the data needs of the other party), and data analysis (much enjoyed by most researchers, but often seen as something akin to tax filing by community members). To insist too slavishly on “equally” engaged within each phase can lead to some tedious and potentially exploitive relationships when the community members and researchers are neither trained in the same skills nor holding the same resources is to distort the intent of shared responsibility. Minkler settles, then, on the term *equitably* (rather than equally), implicitly giving more play to the needed adjustments to these prior inequalities and explicitly laying the emphasis on the “deconstruction of poser and the democratization of knowledge.”

This explicit nod to democratization of knowledge can be traced in both traditions that Minkler cites as converging to give us our contemporary understanding and precedents for participatory research: the Lewinian social psychological work on participatory

action research and the adult education and technical assistance work in developing countries.

THIRD CHALLENGES: CULTURAL HUMILITY VERSUS TECHNICAL HUMILITY

Once the governance issues are settled with an acceptance of rules of engagement and the contributions each party can bring as added value to the joint research enterprise, disputes will arise nevertheless as historical grievances and stereotypes play out. For example, if a few participants see racism and others (of color) do not, are researchers to conclude that racism was at play and some community participants were simply unwilling to acknowledge it? I have observed this type of heterogeneity of perceptions within a complex CBPR project, where some (Blacks) were inclined in this interracial, interethnic collaboration to view the Hispanic participants as insensitive to the Black experience and to view the university researchers to be more aligned with the Hispanic participants because they took the trouble to translate everything the Spanish-speaking participants said into English, inevitably giving the Hispanics more air time at the meetings. The researchers found themselves caught in a withering crossfire of usually subtle but often barbed insinuations and their meetings seemingly ending in stalemates.

The need for shared understanding of separate histories and experiences must be given sufficient time, and cultural humility is essential throughout the collaboration, but this must be balanced with the need to move forward and avoid becoming mired in endless replaying of the past. This often becomes a trade-off between ethical concerns and practical concerns and is one of many instances in which this trade-off must be weighed. Cultural humility must be balanced against respect for everyone's time and the best use of everyone's expertise. Researchers also need in this balancing to accept their identity with a race or class that shares some if not most of the blame and culpability for the past wrongs but must not become such punching bags that nothing is done to make the best use of their potential contribution to the joint effort to correct those wrongs.

KEEPING FAITH AND FOCUS

These examples of the trade-offs between honoring history and getting on with the task at hand, equitably and with humility, seem from my experience to illustrate the overriding ethical challenge in participatory research. This challenge can be summarized as the playing out of the ethics of social justice and the John Stuart Mill ethics of pragmatism, seeking the most good for the most people. Public health struggles with these two pulls at every turn in program planning, implementation, and evaluation. We cannot be surprised that it plays similarly in participatory research directed at public health issues.

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