Ethical Validity: Expecting the Unexpected in Community-based Research

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Abstract

In this paper we suggest that *ethical validity* is achieved when the research process is consistent with the ethical principles of all research partners. This is particularly relevant when working with Aboriginal communities. The engagement of communities as research partners can complicate ethical issues with cultural differences, political factionalism, community research fatigue, fear of stigmatization, and other conditions that mitigate against readiness to participate in research. The case examples provided here emphasize the dynamic nature of the community-academic research environment, with cautions that there are times when the research process should be reevalu-

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ated, put on hold, or even discontinued completely. We match ethical challenges with suggestions for best practices.

Key words: community-based research; ethics; methods; readiness, validity

INTRODUCTION

There has been a surge of interest and activity around the process and practice of participatory action research in the last few years (Israel et al., 2005; Macaulay et al., 1999; Minkler and Wallerstein, 2003). Current approaches move away from a postcolonial stance of expert-subject, the rigor vs. relevance dilemma (Friedman, 2001), and problem-based focus, to what is sometimes called collaborative inquiry (Kelly, Mock, and Tandon, 2001), co-operative research (Heron and Reason, 2001), or appreciative inquiry (Ludema, Cooperider, and Barrett, 2001; Pyrch and Castillo, 2001). These approaches all fit under the umbrella of Action Research or Participatory Action Research, and include local experience and skills as valuable knowledge contributions to research design and outcomes. Useful discussions are taking place on the Internet such as the web site for sharing resources and information on community-based participatory research, sponsored by Community-Campus Partnerships for Health (http://www.ccph.info), and the newly established Centre for Participatory Research at McGill University (PRAM) (http://pram.mcgill.ca/). Other such networks and institutes are appearing as well, formalizing collaborative research partnerships with community organizations beyond academia. Much of this research is applied, drawn from the fields of sociology, education, anthropology, social work, business, political science, and health. The approach, with its focus on collaborative teams, inclusion of various kinds of knowledge (Edwards and Gibson, 2008), and research outcomes that can precipitate change, is a departure from the more traditional objective perspective (Boser, 2006; White, 2006) and has been welcomed by communities. They can now become active partners in research where they had previously been the passive subjects of scientific studies (Chambers, 2008; Kindon, Pain, and Kesby, 2008).

Such research partnerships[2] are complex, and fresh ethical challenges arise (Fadem et al., 2003). Lincoln (2001, p. 127) observes,

> Formalistic protocols do not go nearly far enough in the intimate, face-to-face, democratic work of action research. Consequently, research teams are revising

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2   In this paper the term "research partnership" includes all partners on a project team: community, academic, government, etc. Each team will be different.

> the codes daily, working through intricate interlocking relationships built on trust and caring ... with little formal guidance.

The primacy of the community context in the research process is now an accepted component of research theory and models (Winkler, 1993). Considerable work also has been done by Aboriginal groups regarding ethical issues from a cultural perspective (Patterson, Jackson, and Edwards, 2006; Glass and Kaufert, 2007; Government of Canada, 2005; Macaulay et al., 1998; Martin-Hill and Soucy, ND).

Defining Ethical Validity

In the past decade, the concept of validity in qualitative research has been examined and defended. Such discussions refer to external validity, or the generalizability of the results, and internal validity, or the degree to which the data match reality. Cresswell (1994) argues that although qualitative studies are not necessarily replicable, elements of the theory or protocol may be applicable beyond the research setting. Levin and Greenwood (2001, p. 105) argue that, "the credibility/validity of research knowledge is measured according to whether actions that arise from it solve problems (workability) and increase participants' control over their own situation." Similarly, although internal validity is harder to pin down, methods such as member-checking and gathering data from various complementary sources can strengthen the authenticity of the data (Mays and Pope, 2000). In their comprehensive review, Eriksson and Lindstrom (2005, pp. 462-3) discuss face validity (comprehensibility of the questionnaire), consensual validity ("the agreement of experts that a measure is valid"), construct validity (the effectiveness of the structure of the survey in measuring the target issue), criterion validity (comparison of present scale with other standardized instruments), and predictive validity (the predictive capacity of the scale). Finally, Peter Reason (1994, p. 327) suggests that, "The validity of [the co-operative inquiry] encounter ... rests on the high-quality, critical, self-aware, discriminating, and informed judgments of the co-researchers, which may also be called critical subjectivity," recognizing the different perspectives of the various partners.

We suggest that *ethical validity* is achieved when the research process is consistent with the ethical principles of all research partners. This is particularly relevant when working with community partners. This approach increases the validity of research by recognizing contextual factors within the research environment that are often overlooked with more structured approaches (Gibson, 2004).

With communities as full research partners, ethical issues can become complicated. The complexities of research relationships at the outset of a study require careful examination to identify and ensure sustainability of what we call ethical validity. There are situations wherein research should not be started, or should be paused or even stopped, in order to prevent harm to the participants or the community or both.

In this paper we identify ethical challenges for research teams. We provide illustrations from our experience, while preserving community confidentiality, and we match ethical challenges with suggestions for best practices. Our premise is that in the process of seeking and sustaining ethical validity in our research we can identify challenges to ethical integrity early on, and identify opportunities to mitigate or prevent potentially harmful consequences. This process can then lead to stronger partnerships and better research outcomes (Canadian Aboriginal AIDS Network, 2006).

Political Challenges

Participatory Action Research, by definition, promotes change within the research communities; thus much PAR is inherently political. There are a variety of agendas for any research project (Gibson, Gibson, and Macaulay, 2001), some explicit, some not. As the framework for a research project is established, unanticipated political motives of the partners may come to light. For example, the research may be used to further factional political aims that affect the research process and/or potential outcomes. The project may require reassessment, postponement, or discontinuation if it is no longer consistent with the goals of all partners (Williamson and Prosser, 2002).

The leadership within a research community can be changed by elected terms of leadership positions or other circumstances. Burhansstipanov, Christopher, and Schumacher (2005, p. 72) observe that, "If a project is strongly identified as being supported by the previous tribal leadership, the incoming tribal leaders may refuse to allow the program to continue to evolve"; hence the importance of a long-term commitment that overrides changes in leadership. For most PAR projects to be successful and the results sustainable, a formal written commitment from the community leadership is essential. Without this the research project will be at risk, particularly if the study is addressing sensitive issues over a period of time. Sustained leadership support contributes to an ethical research environment.

In one project, the community agenda shifted with changed leadership following an election. It was necessary for the new leaders to turn their

attention to immediate tasks of governance; support and commitment for the research suddenly stopped and the responsibilities of several research team members were redirected to the political reorganization process. A year later the community leadership was again ready to take up the project. The delay in the project had implications for funding agencies with specific deadlines for expending grants but, in this case, an extension was negotiated. We suggest that research teams identify a well-known and trusted champion within the community, not necessarily a political leader, as a strategy for ensuring community memory and continuity of support through leadership changes. This person is kept informed of the research process, but may or may not be an active team member.

On another occasion, we were asked to provide guidance to a large team, gathered primarily for political reasons, to address a sensitive issue around community drug use. As the day-long meeting progressed, factionalism based on historical rivalries and racism became evident, and the group dynamics prevented consensus on ethical research protocols, despite the initial nominal commitment of the group members. Several of the leaders became aware of these factors, and the group dissolved with no further meetings. The historical rivalries were too deep to overcome in this forum. Had the research continued, it could have reinforced the local divisions. A healthy research climate could not be established at that time and with those individuals.

Another research project overrode the tensions of potential factionalism by focusing on a commitment to address the common threat of tuberculosis. This promoted a strong team wherein tensions, occasionally acknowledged with humour, did not weaken the overall partnership. If an issue such as TB or youth addictions is a priority for all players, the commitment can sometimes overcome differing agendas, jurisdictions, and rivalries.

The other side of this coin is the perspective of participants in sensitive projects when they are interviewed by trained, local, community-based researchers (CBRs) in small communities. Long-term personal relationships may be damaged for both CBRs and participants when sensitive data are collected. Both parties may feel at risk in interviews or surveys with friends and neighbors. Training local researchers in formal consent processes, appropriate data collection techniques, and maintenance of confidentiality contributes to participant trust and confidence. In one community, the lead CBR assigned local researchers to work in teams of two when conducting interviews. By providing balance between gender and age, and

appropriate matching of researchers to participants, the trust of participants was strengthened and the collection of quality data was facilitated. Confidentiality is best assessed on a continuum, revisited regularly within the community context (Jansson et al., 2006).

Open discussion and support of leaders at the outset of the project is paramount. In small communities, working with the largest, most inclusive sample possible, e.g., all high school students, or all parents in the community, or all Elders, can reduce concerns about confidentiality. In such research projects it is also important to ensure that appropriate support, such as Elders and counsellors, is available for researchers and participants alike.

Confidentiality

As we explore the ethical principles that guide research, the dynamic nature of the research environment is paramount, and ethical issues must be revisited regularly. In small communities, it may be unrealistic to promise absolute confidentiality and anonymity. Furthermore, community team members may hold several roles within their community, (e.g., community leader, program manager, Elder, research team member). In one project, an Elder had chosen to be present in every interview to support the participants, although this was not part of the original research design. This was discovered through the team review of several early transcripts. The Elder was serving as both a researcher and a resource for the participants; the conflict between these roles was influencing the responses of participants, and biasing the data. Interviews had been influenced both directly and indirectly by the Elder's presence and confidentiality had been compromised. After some discussion, the Elder was invited to participate in the focus group gatherings later in the research process to provide guidance about dissemination of findings, rather than attending the actual interviews. It was also agreed that the Elder could be an optional resource for participants after the interview if requested by the participant, and otherwise, identities of community participants would remain confidential. The Elder's role was confirmed as a community resource, rather than a member of the research team.

Potential Stigma

Topics such as drug use, fetal alcohol spectrum disorder, family violence, and suicide are extremely sensitive. Communities hesitate to conduct research on sensitive issues: the potential for a negative public image, and

identification with a disproportionately high incidence of a particular condition, reflects badly on the reputation and image of the community and its leadership. Media coverage reflecting negative profiles of communities, based on statistical research outcomes, such as rates of family violence, sexually transmitted diseases, suicide, etc., contributes to an unwillingness to address these issues. Over time, through following community protocols to address sensitive issues, and allowing time for partnership building, communities often reach a place of readiness, an ethical space that feels safe with researchers from within and beyond the community (Ermine, 1995). One community was negatively featured on the front page of a national newspaper on the day of the first research team meeting. The community partners, who had initiated the discussions, overcame their trepidation through discussions of the implications of the newspaper article, and the difference that inclusion of positive information could have made to the community's self-image. They made a decision to conduct capacity-building research on existing and potential strategies to reduce the health risks featured in the article. The shift to a positive, capacity-building approach made all the difference, confirming that a resilience-oriented approach is a useful strategy for sensitive research issues (Edwards et al., 2008).

Sensitive issues can create conflict for community leaders; for example, an unhealthy individual may not be willing to approve a project around family violence or substance abuse. The issue may be too close to home for some leaders, concerned that their own role in perpetuating an unhealthy situation may be revealed. Only time, and a new set of leaders, can change such situations, despite the best efforts of locally committed people. To continue to conduct research on a sensitive topic in such a research climate is to risk increasing tension and factionalism within the community.

The importance of developing ethical protocols at the outset regarding confidentiality, ownership and access to data, and control of dissemination of research results, promotes the safety of the community throughout the research process (Macaulay et al., 2007). There may be occasions where the results of a study on particularly sensitive issues are never published, but remain with the community, to be applied in community actions and programs. The right to publish must be part of a formal agreement, and subject to review by community and academic partners. The right to such a review should be part of the formal agreement, at the start of the research, framing shared ownership of the data and responsibility for dissemination of the results consistent with the ethical values of all partners.

COMMUNITY CAPACITY

As opportunities for research and capacity building occur, projects can strain community resources. A community may decide that it is ready to work on a research project, permissions and commitments may be forthcoming, and funding may even be in place. But as the initial enthusiasm wears off, other priorities intervene, meetings are missed, resources languish, and deadlines become unrealistic.

Furthermore, as an Aboriginal community becomes active in research, it may be inundated with invitations to become a partner in research projects. In communities with small populations, the leadership and those who provide management and coordination often find themselves overburdened. Community enthusiasm can wane when a number of unrelated projects are proposed by researchers who do not know each other, and who have not taken the time to build up trust with the community. The lack of co-ordination creates an additional burden for the community. Sometimes this situation can be addressed by reassessing resources, training new personnel, finding new money, adjusting the timeline, or revisiting the research goals (Marois, 2005).

In one community high school, the principal was overwhelmed with requests for use of the school and access to the students for research projects, once it was evident that she had welcomed the opportunity for one project. With some reluctance, she had to refuse several projects that would overtax her time, the students' school hours, and the facility itself, selecting only those projects that best met school and community priorities.

In another community, the research coordinator asked the academic partners to make sure that we talked to the researchers working on other projects in and around the community to explore opportunities for sharing resources. He was tired of one-off research projects that used community time and resources in data collection, provided short-term focused training to community members, and yet contributed nothing to the long-term success and capacity of the community. He observed that training often is not sustainable and trainees lose their skills, while the scholars go on to receive other grants and degrees. When providing research training, a long-term project with incremental research activities, or a series of sequential projects using the same people and skill set, helps to make the capacity building sustainable within the community. Capacity-building strategies should fit with long-term community needs and goals to be ethically valid.

Another solution, adopted by a number of communities in several countries, is to establish internal procedures for reviewing, approving, and coordinating various research projects within their boundaries (Macaulay et al., 1998). Creating a community research advisory committee to guide a particular project can be a first step towards a strategy for sustained research governance within the community. This may require some capacity building, but once local research review mechanisms are in place, communities have control over what studies are done, a voice in identifying priority research areas, and access to the outcomes. This maximizes relevance of results to the community. Such a committee may also develop a process for community ethical review. Finally, the most certain way to compensate community agencies and organizations for administrative costs of managing research grant budgets, pay roll, etc., is through research agreements for such support with universities and colleges (Holmes et al., 2002).

The cost to communities of building research partnerships and monitoring activities and outcomes is seldom considered by funding agencies. Granting agencies fund academics but do not usually provide resources to ensure community capacity to participate. A few foundations are providing leadership in this area of funding. In their grant applications some researchers are also advocating for compensation for community partners, for whom research is often an addition to an already full agenda.

COMPLEX RESEARCH ISSUES

The issues facing some communities can appear deceptively simple: contaminated water; disturbed hunting grounds; mine tailings piles. Each of these challenges has a clear base for evidence, and a potential solution: identify and remove the source of water contamination; move the anticipated road construction to another place beyond the wildlife trails; remove tailings piles and treat the damaged land. These are deceptively easy solutions to large and complex issues. Evidence must be gathered from within the community and several complementary disciplines before appropriate solutions can be designed. Community commitment in such cases is easy to confirm, while government and corporate commitment, also necessary for such studies, is more difficult. One strategy is to begin with a small pilot study to gather initial data, laying the foundation for a larger, more extensive proposal. This strategy also prevents raising untimely and unrealistic expectations within the community, another potential ethical dilemma.

Limited Academic Capacity/Resources

Now that some organizations and communities see research as a place to begin solving problems, and academic partners as sources of expertise and occasional funding, requests can arise when academics are unable to respond in a timely fashion. Just as community members can be overcommitted, researchers may find their plates full when opportunities for partnerships arise. The time commitment to be part of a research team can conflict with teaching responsibilities, preexisting research commitments, and administrative duties. In some cases, funding is available, but not the required expertise. It is tempting to participate anyway, but the results can be disappointing, with increased workload, weak partnerships, and superficial or inappropriate outcomes.

Best Practices

Our examples emphasize the dynamic nature of the community-based research environment, cautioning that sometimes the research process should be reevaluated, put on hold, or discontinued completely. For all of the scenarios, there may be solutions such as bringing in facilitators or additional funding. Many potentially tense situations can be prevented by negotiating ethical guidelines, partner roles, and responsibilities (Gibson, Gibson, and Macaulay, 2001), as well as data management agreements, at the outset of the project (Potvin et al., 2003). Other situations may be identified and addressed early on with a readiness assessment that measures stages of community preparedness to engage in research (Edwards and Gibson, 2008, Edwards et al., 2000). Research is done by people, however, and the real lives of all partners can intervene. A responsible, ethical research process, aware of emergent situations, makes room for innovative solutions. And sometimes, not doing the project at that time in that place is truly a gift to the community.

In one case, it became clear that we simply could not continue the project, as the attention of the community leadership and the community researchers had moved to another place because of political priorities, and would not be active again within the funding parameters. The decision to discontinue the research was actually viewed as a relief by the community partners, who were thankful that the pressure to participate was off. We were able to transfer the funding to a similar project, in consultation with the funding agency. The initial partnership survived and eventually we collaborated on another research project.

Ethical Research Agendas

Validity is a complex concept. As Russell Bernard (1994, p. 786) observes, "In the end, we are left to deal with the effects of our judgments, which is just as it should be. Valid measurement makes valid data, but validity itself depends on the collective opinion of researchers." The concept of ethics can be equally slippery, especially when working in the space between cultural and academic ethical principles (Flicker et al., 2007). Thus, to paraphrase Bernard, ethical practices produce ethical research, and ethical validity depends on the consistency of the collective principles of the researchers. Enthusiasm for the adventure of community-based research must be balanced by routinely touching base with the range of ethical perspectives within each research environment. Developing strategies with community partners to establish, ensure, and measure ethical validity will evolve within trusting research partnerships.

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