


The Ethical Implications of Community-Based Research: A Call to Rethink Current Review Board Requirements

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Abstract

Researchers need to provide evidence that they have met ethical requirements before entering the field—rightly so, since the power and privilege embedded in academic researchers is considerable. However, given the calls for universities to decolonize and democratize research, we need to question whether the ethical norms developed to cater for objective, researcher-driven enquiries are appropriate and sufficient to ensure ethical conduct for qualitative designs that are more subjective, participatory, and community-based. This conceptual article argues for the need to rethink the standards against which ethics boards evaluate community-based research projects and suggests some ways this could be done.

Keywords

ethical requirements, community-based research, participatory action research, qualitative methodology, collaborative research

What Is Already Known?

Specifically in the social sciences and humanities, there is growing acceptance of the idea of working in partnership with communities, rather than doing research “on” them and reporting findings “about” the issues they face. Current ethical protocols are not appropriate or sufficient to cater for participatory, community-based qualitative methodologies.

What This Paper Adds?

This article takes deeper the discussion on what ethical requirements participatory forms of research necessitate, drawing on specific examples from the field of educational research. It suggests some practical ways that this can happen, a step that needs to be taken if we are to advance the debate from mere talking to taking action to make community-based research more ethical and true to its basic tenets.

Introduction

Amid debates about the relevance of the university to current and future society (Nyland, Davies, & Clarke, 2016), there is increased pressure on these institutions to boost their social responsibility by engaging in research that responds to the real-world challenges facing society, on a local as well as a global scale (Benneworth, 2017). Specifically, in the social

sciences and humanities, there is growing acceptance of the idea of working in partnership with communities, rather than doing research “on” them and reporting findings “about” the issues they face (Hall, Tandon, & Trembley, 2015). Community-based research (CBR) has become the blanket term used to describe research that “seeks to democratize knowledge creation” (Strand, Cutforth, Stoecker, Marullo, & Donohue, 2003, p. 9) through taking action to attain change toward a more just society. This means that CBR is inherently political since it aims to challenge and change systems that maintain inequalities. The pursuit of knowledge democracy in research requires the use of democratic modes of enquiry that include all stakeholders in knowledge production; likewise, it entails using knowledge to strengthen democracy by including everybody into democracy building (Stern, personal communication, June 16, 2017). CBR thus not only creates knowledge products but also in itself is a process of learning and development which has the potential to change society

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through changing individuals and organizations. As Anderson (2017, p. 428) explains, participatory forms of enquiry have strong pedagogical and action components, in addition to the research aims.

The role of the academic researcher working in collaboration with community partners then becomes that of facilitator, whose task is to raise the consciousness of the community about the possibility to take action to improve their lived realities; to use the privileged position of academic to access human, material, and knowledge resources to support learning and development of all collaborators; and to be a partner in the process of knowledge production, rather than the chief director of the engagement. Entering into an educative partnership, where the knowledge of the community is valued as much as the knowledge the academic researcher brings, is not an easy task for researchers; the majority of whom are groomed to believe knowledge must be generated by academics through an objective and neutral process in order to be regarded as “scientific.” Yet, in contrast to the often voiced opinion that participatory designs do not meet the rigor required of academic research, they in fact require more rigorous designs since they are fostering action that has implications for peoples’ lives (Gutierrez & Lipman, 2016). CBR partnerships are as multi-layered and complex as any other human relationship (Brydon-Miller, 2013) since they involve learning and change at individual, group, organization, and ultimately societal levels. And herein lies the problem—the current ethical protocols are not geared to ensure that such relationships are entered into, maintained, and strengthened in ways that are ethically acceptable to all partners. This begs the question: How can we democratize and decolonize research if we are curtailed by ethical processes that are out of kilter with the principles of CBR?

This article is not a call to relax ethical requirements for qualitative approaches to CBR but rather to change the criteria against which strict ethical standards can be evaluated to ensure that they cater for the dynamic, complex, and political nature of such projects. This nature entails a gradual shift of power to the nonacademic members implying that, *inter alia*, perceptions of ethical behavior, the need for “protection,” and ideas of what to do with the knowledge produced will change as participants develop their knowledge, skills, and leadership capacity through involvement in the research process. A once-off ethical approval involving only university partners does not cater for this: Ongoing critical reflection on such issues is needed by all parties throughout the partnership to ensure the research process remains true to the moral code of participatory research.

I was also prompted to address this issue by my concern at the number of qualitative research theses and articles I was requested to examine or peer review that claimed a CBR design, but that in fact followed processes and used methods that were little different from traditional, researcher-driven studies. Was this because academics did not have a good grasp of what CBR entails? Or was it because the fear of not getting ethical approval may have had an influence as researchers attempted to adhere to ethical requirements more geared for nonparticipatory designs? In either case, there are ethical

implications since a well-explicated and justified research design is a vital criterion of ethical approval.

Other scholars have called attention to the need for thinking differently about ethics in a participatory research design (see e.g., Brydon-Miller, 2013; Eikeland, 2006; Löfman, Pelkonen, & Pietila, 2004), but in this article, I present some practical suggestions as to how these processes could look, based on existing literature and my own experience in community-based educational research in a developing country where the gap between the rich and poor is one of the widest in the world (World Bank, 2017). Higher education as a system and the researchers within it are overwhelmingly part of the “rich” group, which brings issue of power and privilege to collaborative relationships with community members, many of whom are denied the basic essentials for living a dignified life. The ethical imperative to ensure that engagement is mutually beneficial, educational, and enabling for all participants is particularly pressing in contexts of such inequality. Although this argument stems from my experience in higher education in South Africa, I believe it is relevant on a global scale as universities struggle to decolonize, democratize, and transform their core business of teaching, research, and community engagement to make it more relevant to current and future social, economic, and political scenarios (Heleta, 2016). I begin with a discussion of the basic tenets of CBR and their ethical implications for the democratic generation of knowledge within community–university research partnerships. I then explicate how each of these principles can be used to develop standards against which ethics applications which purport to be community-based should be judged, in order to ensure they adhere to the ideals of this approach to research.

The Ethical Implications of CBR

The aim of CBR is to generate knowledge to support action toward a more socially just situation. It operates from an emancipatory paradigm, which Lather (1991) elucidates as having a critical, praxis-oriented, and educative stance. Since many groups have been marginalized and colonized to the extent that they believe they are helpless to take action, or lack the resources to do so, CBR opens up space for the public academic to trouble dominant epistemologies (Said, 1994) and partner with community to facilitate learning and development to the extent that they can improve their lives on a sustained basis (Hall, 2009; Hoballah, Clark, & Abbas, 2017). Thus both parties benefit—community partners improve their capabilities (Walker, 2005) or freedom to make choices to improve their lives; academics meet their social responsibility mandate by providing intellectual leadership to advance thinking about social problems and facilitating action to address them, while improving the research outputs of the institution and their own academic curriculum vitae (CV).

So, the benefits of CBR to universities are not inconsiderable. The onus should thus be on the academic institutions to ensure that such research is conducted in an ethical way, but this raises the question of what additional or alternative ethical

requirements are needed when the research is conducted in partnerships outside of the academic world, where diverse values, cultures, and knowledge systems bring different interpretations of what is ethical conduct. The ethics review boards of universities are based on the principles contained in either the Helsinki Declaration (Human & Fluss, 2001) or, in the case of the United States, the Belmont Report (United States, 1978): respect for persons, beneficence and justice, operationalized by the processes of informed consent, assessment of risks and benefits, and strict guidelines to ensure fair selection of participants. Although they have both been amended to include the social sciences and qualitative approaches within their scope of practice, they were originally developed to protect humanity (and animals) against unscrupulous biomedical research(ers). They position people as human “subjects” in need of protection against researchers who will “utilize” them in data collection to generate their own theories, rather than recognizing the assets they bring as participating partners in the process. The central principles of CBR, namely, collaboration, democratic knowledge generation, and social action (Strand, 2000), are designed to protect participants from such exploitation. As such, they ensure intrinsically ethical practice, but they also raise additional ethical concerns that are not usually addressed in current review board approval processes. The inappropriateness of the review board requirements is a situation, which opens up the possibility of the community not being able to participate, learn, and develop as CBR intends them to. I now offer some examples to illustrate my point, based on the ethical requirements common in most universities:

The *expertise of the researcher* to undertake the research must be proven in the form of an ethics training certificate and a CV that illustrate their knowledge and skills to undertake a particular methodology. However, the ethics training, at least outside of the social work and psychology faculties, does not cover participatory forms of research and most postgraduate research courses continue to focus only on quantitative, qualitative, and mixed-methods designs. This is worrying, since the nature of CBR entails having honed facilitation and communication skills; being able to recognize one’s own privilege and power and how it impacts on the research relationships; and ensuring that values such as inclusion and democracy underpin all interactions (Dockstator et al., 2017). Although some of these competencies are important when conducting interviews or employing other qualitative methods, they are less so when the researcher drives the process and merely interacts for an hour or so to collect data, rather than working collaboratively on a long-term basis. I think of one example where a PhD student researching with teachers in management positions in a school continued to let the “teacher-creature” in her dominate, so much so that she exposed the lack of knowledge of the participants, who then withdrew from the project, hurt, and ashamed—how many others enter into community settings without the necessary skills and perhaps cause more harm than good? The need to reflect carefully on the intricacies of participation, power, privilege, and

relationships is paramount in CBR *before* entering the field and requires constant monitoring.

The rigid rules about *selection of subjects*, designed to protect people from undue persuasion to participate and to ensure fairness in inclusion criteria, require that “independent” people need to approach the participants and explain the risks and benefits and what is expected of them in the study before the researcher enters the field. This negates the relationship of trust that the community-based researcher has to build up over time. It also implies that the researcher knows all the risks and benefits without consulting the people involved. One student of mine had been working informally with a group of teachers over a period of 2 years to help them improve their teaching and school infrastructure. They asked her to help them learn to cope with the stress they were feeling, emanating from working in a very underresourced setting, and she decided to use a CBR design, participatory action learning, and action research (PALAR; Zuber-Skerritt, 2011) to involve them in researching sustainable ways to improve their well-being. The review board insisted that she could not recruit these teachers personally, even though they had approached her and were already “recruited” so to speak; a complete stranger had to visit the school and explain a long informed consent letter to the teachers and then ask them to go away and think about it; then bring it back to school and call the independent person in again to sign it in her presence. And in the 8 months it took to gain ethical approval (university systems are notoriously slow), the researcher was not allowed to communicate with the teachers. Needless to say, they felt that they had been dropped, that she had not responded to their request for help, and they were now not willing to participate in this project or meet with a stranger to discuss it. The process insisted on by the review board had caused emotional harm to the teachers, rather than the intent of protecting them. Such processes are appropriate when more objective forms of enquiry are being followed, but in the case of a participatory, collaborative process like CBR, perhaps we need to rethink how we do things.

The *methods of data generation* in CBR are multiple and participatory (Hall, 2009). Apart from the capacity point discussed above, this also has implications for the ethical requirements of anonymity and secure storing of data. In CBR, data, particularly visual and arts-based forms, are often out in the public domain because they are exhibited in or shared with the wider community; the ownership of the data has to be negotiated as it has been generated by the participants and not “collected” by the researcher to be stored under lock and key or password for 5 years. The researcher can do this, but the participants must also be able to use it as they see fit, which includes sharing it on a public platform. In terms of anonymity, the very notion goes against the idea of coproduction of data—if the researcher is recognized for writing an article to share the knowledge generated, then the participants should be mentioned by name, if they so wish, on any output. The participants in one study I supervised, all community volunteers in a school, insisted on having their real names and pictures used in the thesis of the PhD scholar who was working with them; they

requested help in developing a working manual from the theoretical model generated that they could use to train other schools to start a volunteer program; and they asked for a graduation ceremony in the community where they could be recognized for the knowledge they had generated in “our” PhD. This is an example of participants constructing their own ethical requirements, which were in total harmony with the principles of CBR—but that either were in conflict with the university ethical requirements (anonymity of participants when reporting) or were not conceived of as being ethical imperatives (dissemination of findings in a way that offers sustained benefit; public recognition of local knowledge).

These are just a few examples of how the ethical implications of CBR are not in alignment with current guidelines that are still geared toward traditional, nonparticipatory forms of research (Shamoo & Resnik, 2015). The political and relational nature of CBR requires a rethinking of review board processes to ensure that they enable the core CBR principles to be operationalized so that collaboration toward learning and development, leading to social action to improve the lived experiences of participants, can result from the engagement—as well as the production of theses and articles. Some suggestions as to how this could be practically achieved follow in the next section.

Rethinking the Ethical Process for CBR

Using the three basic principles of the Belmont Report (respect for persons, beneficence, justice), I will now make some suggestions as to how these can be enhanced within CBR studies by adopting alternative approaches to operationalizing them. Such approaches will enable the foundational principles of CBR to be embodied by all participants, contributing to the democratization and decolonization of research, a very hot topic in academia in recent years. The three principles are not mutually exclusive of course but are discussed separately for ease of understanding.

Respect for Persons

This principle requires that “individuals should be treated as autonomous agents” (United States, 1978, p. 2) and that those who are regarded as having reduced autonomy should be protected. While this is a perfectly moral and sound requirement, the definition of “reduced autonomy” can be problematic in participatory forms of research. CBR holds respect as one of its non-negotiable values; it implies acknowledging the ability of persons to learn and develop and make decisions, in spite of the adversity they may face. Current ethics documentation declares, for example, all people who live in contexts of poverty are vulnerable and in need of protection—implying that the majority of citizens in South Africa are “vulnerable,” an idea that feeds into and maintains a colonized mind-set, rather than contributing to the emancipatory outcomes which CBR promotes. The pressure on researchers to show that they have protected the identity of participants may actually harm the dignity of people and their potential to learn to make their own

decisions. The many studies using a youth participatory action research design (see www.publicscienceproject.org/ for just some examples), belie the myth that young people, for example, are vulnerable, helpless, and must be protected through anonymity. Although I have to sign a Researcher Code of Conduct which states: “I will acknowledge the names and roles of those who made significant contributions to my research in publications, including writers, funders, sponsors, and others, but do not meet authorship criteria.” (http://www.nwu.ac.za/sites/www.nwu.ac.za/files/files/i-governance-management/policy/2P-2.4.3.2_plagiarism%20and%20dishonesty_e.pdf), there is no provision for the recognition of participants since they should remain anonymous.

In CBR, since participants (i) identify the research question, (ii) codesign the research process, and (iii) cogenerated/analyze the data, they ethically have to be acknowledged as main contributors to the research. The question of who meets “authorship criteria” is not as straightforward since international guidelines recognize Criteria i–iii above as sufficient for coauthorship (see <http://www.sciencemag.org/careers/2001/03/ethics-authorship-policies-authorship-articles-submitted-scientific-journals>). However, these were developed for the natural sciences and there are other views on authorship within the humanities field, where authorship is more linked to article writing, rather than the research process (see https://publicationethics.org/files/u7141/Authorship_DiscussionDocument_0_0.pdf). Again, this points to the need to address these issues as part of the partnership contract before submitting for ethics clearance. In either case, acknowledgment or authorship, identity of participants is revealed, so anonymity does not apply, and may in fact deprive participants of their right to be acknowledged for their contribution. Of course, due care must still be taken not to attribute any statements to a particular person, if these could somehow bring them into disrepute or danger of being harmed in any way—but on the whole community participants in CBR want to be recognized through using their actual names and faces in publications. As Castle- den, Morgan, and Neimanis (2010) explain, “discussion about criteria for authorship when research agreements are drawn up serves to legitimize shared authorship, strengthen the research partnership, and justify final dissemination practices” (p. 29).

Respect for persons is also attained through an informed consent process, which ensures voluntary participation based on a good understanding of what is expected of participants, how they will benefit, and how they will be protected from harm. This is only right, but the current processes of attaining informed consent do not take into consideration the relationships of trust that underpin CBR collaborative partnerships. The letters containing the information are generated by the researchers, often using a generic template, and do not necessarily reflect the needs or wishes of the participants.

Indirectly, respect involves a good understanding of not only the participants but also of one’s own paradigms, beliefs, biases, and privilege. Since critical reflection forms the basis of CBR designs, researchers must be aware of how their own worldviews, attitudes, feelings, and behavior may impact on

the relationship. How might their privilege as professors silence or empower the participants? How does language proficiency affect participation? Reflection on such questions, along with intentions on how to address any perceived problems, is needed before entering the research process and should be required by ethics boards as evidence of having thought about such issues. Since the researcher is part of the process, rather than an objective outsider, and is in fact a powerful tool to generate data (Bourke, 2014), competence in CBR depends on an ability to critically reflect on self. Since most researchers have had little or no formal training in CBR designs, this reflection becomes even more important to show their competence to lead a process of critical reflection and action. This also relates to the principle of beneficence.

Beneficence

This requires participants not only to be protected from harm but also to benefit from the research in some way. In current practice, this requires the researcher to make a list of all possible risks and benefits, some of which seem rather inane, such as “the participants may become tired and I will watch for this and suggest a break” (as seen in a recent application), which implies again that the participants are helpless individuals with no autonomy to say that they need to stop for a while. From a participatory paradigm, it is more fitting that ethical behavior is decided on by all participants and an agreement drawn up to state what benefits they wish to attain, how they wish to be treated in specific circumstances, what risks they can foresee, and how they should be protected from adverse outcomes. Again, the ideal is to do this before ethical submission, so that parties can sign a collective agreement and a representative can accompany the researcher to the ethics board interview to explain for themselves what they have agreed on. This may involve identifying specific values that they deem important to maintain and build the collaborative relationship and how such values should be played out (Brydon-Miller, 2013) and an agreement on how often they should review this. Since CBR designs are emergent, there is a need to constantly monitor ethical practice, rather than just having a once-off signing of a consent letter. One design suitable for CBR is PALAR, which is based on the principles of communication, critical reflection, collaboration, commitment, coaching, competence, and compromise, operationalized through relationship, reflection, and recognition (Wood & Zuber-Skerritt, 2013) and these could be useful criteria which participants might use to construct an ethical agreement and evaluate the research process and relationships on a regular basis throughout the study. Table 1 indicates how this could be done.

Justice

The principle of justice concerns who receives the benefits of the research and it serves to protect people from bearing undue burdens emanating from the study. It is thus linked to the selection of participants to ensure people are not manipulated

Table 1. Example of How Principles of CBR Can Be Used to Construct and Monitor Ethical Partnerships (Wood & Zuber-Skerritt, 2013).

Communication	How can we ensure our communication is dialogical, symmetrical, and inclusive? How will findings be communicated?
Commitment	How can we demonstrate commitment to the project and outcomes?
Competence	How can we ensure we have the capacity and competence to carry out participatory forms of research with all its implications?
Compromise	How can we ensure we listen to other points of view and reach mutual agreement to the benefit of all?
Critical reflection	How can we ensure that we reflect regularly on process, knowledge, and outcomes, including our own attitudes, feelings, and actions that might affect the partnership?
Collaboration	How can we ensure the process is collaborative? What roles do each of us play? Who holds the power at each stage?
Coaching	How can we ensure participants receive the mentoring/capacity building required for authentic participation?
3 Rs	
Reflection	How well are we adhering to the contract?
Relationships	How can our relationship be improved to advance equitable power relations and democratic participation?
Recognition	How will we recognize the contributions to knowledge generation/authorship? How will findings be used?

or exploited and that they benefit from the outcomes of the research (United States, 1978). Since participants in CBR are the ones who determine the problem and research design, we need to think differently about how this principle is operationalized. Community members themselves decide on selection criteria, if any, and make decisions about who will participate and how in negotiation with the academic researchers, again pointing for the need for an initial agreement on the process before submitting the formal ethics application. Using PALAR as an example of CBR, Figure 1 indicates the process of first discussing the context of the study in-depth and coming to agreement on how the partnership will unfold, before commencing the actual study. By engaging in a thorough context analysis, a collaboratively developed partnership agreement can be developed and jointly presented to the ethics board by the academic researcher and a representative of the participating community.

Another issue involves the ownership and accessibility of knowledge generated in CBR. It must be made available free of charge and in open access (Hall, 2009), therefore mere consent for using research in academic publications is not enough—community participants are unlikely to be able to access scientific journals (or to have interest in so doing). This speaks to justice beyond the selection of participants, as highlighted in the Belmont agreement—it requires fair practices concerning proprietorship of knowledge and how it can be used. Since CBR is a

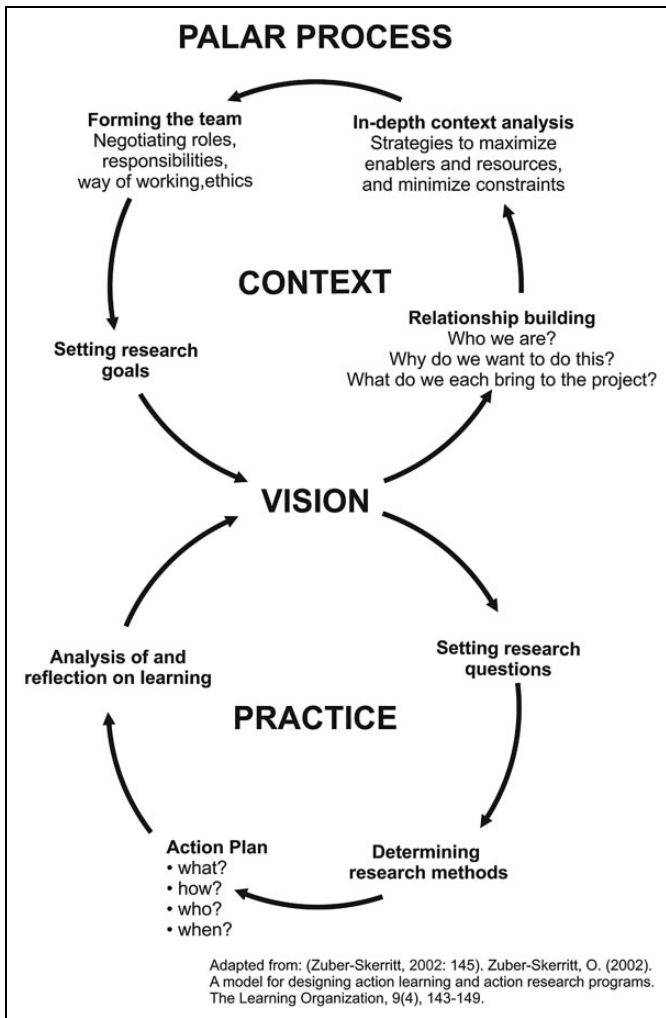


Figure 1. The PALAR research process. Adapted from Zuber-Skerritt (2002, p. 145).

developmental process, this has to be negotiated not just at the beginning of the study, when the partners might not yet be able to imagine what will emerge, but as knowledge is generated and ideas about how it can be used for the good of the community are engendered. Since CBR designs involve cycles of action and reflection, research questions and outcomes are very likely to change as the process evolves and power dynamics shift, making it vital that the research partnership be reviewed on a regular basis, with proof of this being submitted to the ethics committee. As CBR is a developmental process, concrete and useful outcomes for the community should be viewed as an important aim of the study and contribute to the sustainability of the learning (Wood, 2017). The community should decide on the form of such outcomes (e.g., a training program with resources, policy briefs, media releases, newspaper articles, or social media campaigns) to ensure that the knowledge is disseminated among the people who are in need of it and in a way that is easily understandable in terms of language and discourse.

The preceding sections have offered some examples of how we might think differently about ethics for CBR. I am not

suggesting that these are the only issues that we need to take into consideration but offer them as a catalyst for applying our minds to the ethical implications of CBR and how these can be operationalized.

Conclusion

In this article, I have attempted to explain some of the problematics of judging CBR studies against traditional ethical requirements and argued for a need to rethink how we interpret and operationalize the principles of respect, beneficence, and justice as the universal basis for ensuring ethical conduct in research. Due to the participatory nature of CBR and its transformational potential and intent, the procedures required by most ethics boards are neither applicable nor sufficient to ensure that community participation at all stages of the study is authentic, democratic, and developmental. The need for a different approach to ethics for participatory studies has been documented, but this article adds to the discussion by suggesting some practical ways that this can happen, a step that needs to be taken if we are to advance the debate from mere talking to taking action to make CBR more ethical and true to its basic tenets. These suggestions can provide some guidelines for researchers to engage in discussion with their ethics bodies and hopefully assist them in ensuring that their research is a true partnership of knowledge generation that contributes to the generation of useful, relevant, and contextualized knowledge that is valued on both the community level and within the realms of academia. Because, if not, we are in danger of promoting unethical research conduct and transgressing the very principles, we pertain to uphold.

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