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Ethics in Community-University Partnerships Involving Racial Minorities: An Anti-Racism Standpoint in Community-Based Participatory Research

Hélène Grégoire and June Ying Yee

The elimination of health inequalities requires collaborative research approaches that are action-oriented and challenge the status quo. Community-based participatory research (CBPR) has gained recognition as a particularly useful approach for promoting health and reducing disparities. While this approach was developed in large part as an attempt to rectify ethical problems that are common in traditional research (such as the limited relevance and benefits of the research for the community), it continues to pose various ethical dilemmas. In a context where inequalities are racialized,¹ failing to reflectively address these dilemmas can result in furthering the exclusion of racial minority communities.

In order to address racial inequities, we argue for the use of an anti-racism research methodology within CBPR because of its emphasis on transforming research practices that have historically depended on and perpetuated unequal relationships between the researcher and the researched. First, we begin by clarifying why we see CBPR and anti-racism as compatible approaches and we highlight some of the ethical conflicts laid out in the CBPR literature. Next, we offer a few anti-racism strategies and examine the additional ethical challenges that the anti-racism lens enables us to perceive and address.

CBPR and Anti-Racism Research Methodologies

Meredith Minkler (2004) indicates that CBPR is rooted in two main traditions: action research, developed by social psychologist Kurt Lewin in the 1940s as a means to overcome social inequalities, and alternative approaches that emerged in the South from work with oppressed groups. In particular, Paulo Freire's work as an adult educator led to the development of participatory research as an approach that recognizes oppressed people's capacity to identify, analyze and find solutions to their problems and to collectively generate and control their own knowledge rather than letting outsiders be the "experts" on their situation. As a form of participatory research, CBPR acknowledges the strengths and experiences of all partners and attempts to shift the power of decision-making and knowledge production increasingly into the hands of research participants. It provides people with tools and opportunities to critically reflect on their situation, understand underlying causes of their problems, and seek ways to collectively effect change in their everyday lives and in the systems with which they interact.

¹ In Toronto, where the authors live and work, there is evidence that poverty is becoming increasingly racialized (Ornstein, 2006). Racial categories are constructed as different and unequal in ways that lead to social, economic, political and health inequities through a process known as racialization (Galabuzi, 2006). In this article, we use the term "racialized minority communities" to refer to non-dominant ethnoracial communities who, through the process of racialization, experience race as a key factor in their identity. In Toronto, where the dominant and privileged group is White, racialized minority communities are non-White.

Similarly, the task of anti-racism, argues George Dei (2005), is “to identify, challenge, and change the values, structures and behaviors that perpetuate systemic racism and other forms of societal oppression” (p. 4). According to Dei (1996) anti-racism can be defined as: “an action-oriented strategy that addresses racism and other interlocking systems of social oppression” — which may be based on gender, sexual orientation, age, physical ability, etc. — and “challenges the continuance of racializing social groups for differential and unequal treatment. Anti-racism explicitly names the issues of race and social differences as issues of power and equity, rather than as matters of cultural and ethnic variety” (p. 252). It is an approach that recognizes power differentials in research relationships and the privilege that comes with particular racial identities. It provides researchers with an opportunity to critically engage their own experiences in the research process (Dei, 2005). Anti-racism research is sometimes criticized for being partisan but part of its strength lies in making its biases known, in contrast to dominant research approaches that are supposedly neutral even though researchers have their own biases, often rooted in the dominant culture.

Overcoming health inequalities requires creating spaces where racialized communities can work together to affect the conditions that impact on their well-being. Anti-racist CBPR can create such spaces by bringing together different stakeholders to enter into a dialogue, better understand the nature of social oppression and take action to bring about change from an ethically grounded place. We hope that this paper will encourage further dialogue on the integration of these two approaches.

Brief Overview of Ethics in the CBPR Literature

Ethics have emerged as a growing area of discussion in CBPR circles. The literature acknowledges that CBPR raises particular ethical issues that need to be sensitively addressed. In particular, a number of authors have pointed to the inappropriateness of traditional ethics review procedures for CBPR, as these procedures are based in a model known as positivism, which separates thought from action, and subject from object, and assumes that research should and can be value free. Another problem is that emphasis is given to assessing risks to individuals without paying attention to risks to communities.

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Many of the issues identified in the literature arise from the collaborative and cyclical nature of CBPR. In addition to the inadequacy of traditional informed consent requirements, commonly identified challenges include insider/outsider tensions, the sharing of findings that could potentially harm a community (Minkler, 2004), and confidentiality in the context of collaborative data collection and interpretation. Some have explicitly pointed to the challenges raised by the different interests represented and the unequal power relations between them and how these relationships affect how and by whom decisions are made throughout the research process (Boser, 2006).² Fewer still have carefully addressed the complexity of intellectual

² For example, minority interests might be suppressed during decision-making surrounding the choice of research priorities, the analysis and the presentation of findings.

property issues (i.e., the question of who owns the knowledge) in the context of collaborative knowledge generation (Greenwood & Brydon Miller, 2006).

Although CBPR attempts to address some power related issues, not much is written about how to navigate the tricky political terrain of racism in research practice. Indeed, few contributions have been written from an anti-racist stance. Vivian Chávez and her colleagues (2005) note that the “trilogy of race/ethnicity, racism, and white privilege” has often been neglected in CBPR (p. 82). They use Camera Jones’ three-tiered framework for understanding racism, which draws differences between institutional and personally mediated racism, and internalized oppression. Minkler (2004) also uses this framework to explore real and perceived racism in a CBPR project in which she was involved. While this framework is useful, we feel that the literature on anti-racism offers tools, strategies and concepts that can enrich the dialogue on ethics in collaborative research.

Approaching CBPR from an Anti-Racism Stance

We propose approaching ethics in CBPR from an anti-racism stance because we believe this lens can deepen the dialogue and inform solutions to ethical conflicts that arise from dominant ways of thinking about and organizing research. Anti-racism concepts that might be useful in CBPR research, include: (1) how our own personal histories and experiences shape how we understand and interpret the world; (2) how knowledge that is produced through research impacts on personal and collective identities; (3) how institutions privilege traditional forms of research and inappropriately use standards that were designed for traditional models when assessing the value of other kinds of knowledge; and (4) how critical self-interrogation of one’s own values should be an on-going activity. In this paper, we direct most of our attention to the third notion.

Research that concerns racial minority communities typically operates in a context dominated by “white Anglo-European middle-class groups who have controlled academic discourse” (Birrell, 1989, p. 215). Not surprisingly then, traditional research has failed to reflect the experiences and meet the needs and expectations of racial minority communities who are under-represented in the academy. Historically, positivist research has dominated the academy as being the only credible and valid way of creating knowledge. This research paradigm has been criticized for creating and perpetuating the myth that objective knowledge exists. What is deemed to be objective knowledge is largely rooted in a Western worldview. The dominance of this paradigm has resulted in various negative impacts on racial minority communities, including unequal power relations between the researcher and the researched; barriers that limit racial minority communities’ participation in shaping research processes; and the lack of say of research participants about how their knowledge should be used.

To some extent, CBPR has attempted to address some of these issues with its emphasis on collaboration with stakeholders. Yet those working in CBPR rarely directly address the problem of white privilege and institutional racism. Although CBPR and anti-racism researchers both work with stakeholders to find a common understanding about the goals of the research, community-based researchers could benefit from exploring the anti-racist question of how to “work with their subjects in a genuine spirit of collaboration and power

sharing in the context of an open insidious denial of the privilege that comes with particular racial identities (e.g. white identity):” (Dei, 2006, p. 8). An anti-racism stance can enable CBPR to deal with the problem of white privilege and systemically entrenched institutional racism.

CBPR is largely about creating space for those who come from alternative perspectives, such as feminist, queer and racialized ways of knowing, to have a “voice” in the process of research. To do so, however, inevitably creates tension, particularly for those who are in privileged institutional positions and whose dominance remains invisible to oneself. Many studies have, sometimes inadvertently, reinforced negative stereotypes about racial minority communities; this can easily happen when the assumptions of a study are based on a model that emphasizes the deficiencies of a community. When this occurs, the research design, framing of research questions, and interpretation of the research unintentionally reinforce the dominant stereotypical thinking about communities instead of presenting communities as creating healthy acts of resistance to oppression. These studies, although they may have been carried out in consultation with the community, still fail to incorporate meaningful anti-racist analysis of what is happening in the research process. There is therefore a need for those who are in privileged positions and, in particular, those whose research approaches continue to be rooted in the positivist model (knowingly or not) to engage in a form of consciousness-raising.

Institutional review boards (IRBs — i.e., the university- or hospital-based committees responsible for ensuring that research projects are ethical) should set in place the conditions to encourage research participants to be creators of knowledge and resisters of oppressive research. The opportunity for IRBs to engage in critical self-reflection would challenge institutionally entrenched acts of racism. As commented by Chavez, Duran & Baker (2003, p. 85), “institutionalized racism works to establish the dominant culture and its way of doing things, including traditional forms of research as the yardstick that measures and establishes credibility.” In other words, acts of institutionalized racism are perpetuated when IRBs work to legitimate and justify a set of practices that are considered dominant by marginalized communities. Anti-racist institutional change is needed to allow knowledge to come from the community and to be defined in ways that may be different from the dominant cultural norm.

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Approaching CBPR from an Anti-Racism Stance: Two Case Examples

The two examples in this section are based on work carried out with Access Alliance Multicultural Community Health Centre, a community health centre that serves immigrants and refugees in Toronto, Canada. Access Alliance’s mission is to work to promote health and well-being and improve access to services for immigrants and refugees in Toronto by addressing medical, social, economic and environmental issues. Its vision is that of a future in which diverse individuals, families and communities can achieve health with dignity. To advance towards that vision, Access Alliance is committed to engaging in and enabling CBPR as a means of promoting health, furthering the understanding of health inequalities, gathering

evidence needed to make policy change happen and improving programs and services. The organization has developed a statement of values and principles that draws from CBPR principles and the anti-racist framework. These values and principles are: 1) community benefit; 2) capacity-building; 3) collaboration and inclusion; and 4) equity and dignity. Not satisfied with traditional ethics review boards and wanting to ensure that the research taking place at Access Alliance is consistent with both accepted ethical standards and these values and principles, the centre has established its own Research Ethics Committee. All research involving Access Alliance's clients and/or staff needs to be approved by this committee.

June Ying Yee, co-author of this paper works at Ryerson University, School of Social Work, which has the following mission statement: "The Ryerson School of Social Work maintains our work with communities, expressed in our collaborative community-based research, community service and in educational relationships with field placement settings. Most defining is our on-going struggle to stand with communities that experience oppression and marginalization as we pursue our commitment to social justice." Despite the progressive orientation of her department, as a racial minority academic, June struggles on a daily basis with institutional structures that do not address the hidden forms of white privilege and institutional racism found in research processes. By working with Access Alliance, she is able to work through issues of white privilege and institutional racism given the organization's integration of CBPR principles with the anti-racist framework.

In partnership with June and representatives from other community agencies, Access Alliance has received Canadian Institutes of Health Research funding to conduct workshops with racial minority consumer-survivors, service providers from the mental health sector, and policymakers, to explore and address systemic discrimination in the mental health care system. As required by Access Alliance, the project underwent an ethics review process. Access Alliance's ethics review differs from traditional ethics reviews in that it includes questions about the relevance of the research to Access Alliance's mission and vision, community participation, the nature of the partnership, the removal of barriers to participation (e.g., linguistic and financial barriers), data access and ownership, and capacity-building.

The experience of going through such a review created a dialogue amongst the working group members, inviting us to critically reflect on ownership and power issues and to anticipate ethical tensions. In particular, it allowed us to think upfront about how we might use our research design to create processes that would enable equitable access and participation by racialized minority communities who normally are left out of participation in research. This included integrating an educational component into our workshops to ensure that participants would gain something out of them. The working group has had to discuss the question of who has and should have a voice at the table in driving the project. Though most of the working group members are racialised minority individuals, most of us have a degree of institutional power (e.g., academic, executive-director of a mental health agency and other representatives of community agencies). While the working group believes there should be more consumer-survivor participation on the working group itself, increasing that participation is not simple. First, if we are to meaningfully engage racialized minority consumer survivors, adequate funding is needed to pay for their food, transportation, time and cost of participation in the

research process and therapeutic sessions. Otherwise we run the risk of exploiting these communities once again. Secondly, the argument that racialized minority individuals with institutional power cannot represent communities, fails to look at the complexity of who is an insider and negates the premise that the lived experiences of those sitting at the table need to be valued as authentic knowledge. This dialogue will continue as the group plans for next steps to ensure that the research has institutional and policy level impacts.

Access Alliance collaborated with June on another research project that examined the systemic and individual barriers experienced by visible minority social workers in mainstream social service agencies. One of the ethical dilemmas that arose in this study concerned the presentation of the findings. Many interview quotes were obtained from racial minority people about what they perceived to be acts of discrimination. However, when reviewing the data, the steering committee, which was composed of people who were primarily White, reacted with these types of questions and comments: “can you show us any of the findings that show less negative data and more positive data?” or “I do not arrive at the same interpretation and conclusion that you did about that quote.” Such comments prevented the researchers from being able to fully conduct an anti-racism analysis on the data and limited the anti-racism methodology to only guiding the conceptual framework of the study, specifically the questions asked of participants for the research study. As a consequence, the researchers comment that: “In the report, you will find detailed direct quotes from participants in the research to allow for their experiences to be shown explicitly without interpretation. As part of an anti-racism research perspective, there is little analysis by the researchers of the data, rather it is the data that leads and directs the findings. This method acknowledges that no one is free of bias and allows you as the reader to reflect on the data from your own social location” (Yee, Wong & Janczur, 2006). It is evident from the example that different interpretations of the data emerged. Clearly, one’s race, gender, class, and sexual orientation affect data analysis and interpretation. It was frustrating for some to not be able to conduct the analysis from a clearer anti-racist perspective. However, when an anti-racist analysis is applied, readers of the research will often comment that the research is biased and does not look at all sides of the issues. The assumption is that the research was poorly done and quickly came to conclusions that are not valid based on western standards. Being committed to eliminating racial inequalities, therefore, often turns out to be a fine balancing act between maintaining both integrity and credibility.

Conclusion

Almost inevitably, research that denounces racism raises accusations of non-objective and biased findings. It does not rigidly prescribe to the normative standards of traditional research because the methodology required to work in this area needs to shift to a focus on the racism and the way it operates. Yet, due to the denial of privilege by many who act as gatekeepers to the kinds of research that can be conducted, racial minority communities are unable to express what they are truly experiencing even when they are invited to participate in research about themselves. When one combines CBPR and anti-racism research methodologies, one can more clearly see the relationship between politics and research and the need to question how knowledge is produced and oppression maintained, as well as critique social, political and economic institutions for the purpose of taking action against social inequality. Coupled with anti-racism, CBPR has greater potential as a strategy to address health inequalities.

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