

2-8-2018

# Ethical Issues in Conducting Community-Based Participatory Research: A Narrative Review of the Literature

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## Recommended APA Citation

Kwan, C., & Walsh, C. A. (2018). Ethical Issues in Conducting Community-Based Participatory Research: A Narrative Review of the Literature. *The Qualitative Report*, 23(2), 369-386. Retrieved from <http://nsuworks.nova.edu/tqr/vol23/iss2/6>

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## Ethical Issues in Conducting Community-Based Participatory Research: A Narrative Review of the Literature

### Abstract

Community-based participatory research (CBPR) is a methodology increasingly used within the social sciences. CBPR is an umbrella term that encompasses a variety of research methodologies, including participatory research, participatory action research, feminist participatory research, action research, and collaborative inquiry. At its core, they share five key attributes: (i) community as a unit of identity; (ii) an approach for the vulnerable and marginalized; (iii) collaboration and equal partnership throughout the entire research process; (iv) an emergent, flexible, and iterative process; and (v) the research process is geared toward social action. While there is no shortage of literature that highlights the benefits and potential of CBPR, relatively little discussion exists on the ethical issues associated with the methodology. In particular, current gaps within the literature include ethical guidance in (i) balancing community values, needs, and identity with those of the individual; (ii) negotiating power dynamics and relationships; (iii) working with stigmatized populations; (iv) negotiating conflicting ethical requirements and expectations from Institutional Review Boards (IRBs); and (v) facilitating social action emerging from the findings. For CBPR's commendable goals and potential to be realized, it is necessary to have a more fulsome discussion of the ethical issues encountered while implementing a CBPR study. Further, a lack of awareness and critical reflection on such ethical considerations may perpetuate the very same problems this methodology seeks to address, namely, inequality, oppression, and marginalization. The purpose of this article is to provide a narrative review of the literature that identifies ethical issues that may arise from conducting CBPR studies, and the recommendations by researchers to mitigate such challenges.

### Keywords

CBPR, Qualitative Research, Ethical Issues

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## Ethical Issues in Conducting Community-Based Participatory Research: A Narrative Review of the Literature

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*Community-based participatory research (CBPR) is a methodology increasingly used within the social sciences. CBPR is an umbrella term that encompasses a variety of research methodologies, including participatory research, participatory action research, feminist participatory research, action research, and collaborative inquiry. At its core, they share five key attributes: (i) community as a unit of identity; (ii) an approach for the vulnerable and marginalized; (iii) collaboration and equal partnership throughout the entire research process; (iv) an emergent, flexible, and iterative process; and (v) the research process is geared toward social action. While there is no shortage of literature that highlights the benefits and potential of CBPR, relatively little discussion exists on the ethical issues associated with the methodology. In particular, current gaps within the literature include ethical guidance in (i) balancing community values, needs, and identity with those of the individual; (ii) negotiating power dynamics and relationships; (iii) working with stigmatized populations; (iv) negotiating conflicting ethical requirements and expectations from Institutional Review Boards (IRBs); and (v) facilitating social action emerging from the findings. For CBPR's commendable goals and potential to be realized, it is necessary to have a more fulsome discussion of the ethical issues encountered while implementing a CBPR study. Further, a lack of awareness and critical reflection on such ethical considerations may perpetuate the very same problems this methodology seeks to address, namely, inequality, oppression, and marginalization. The purpose of this article is to provide a narrative review of the literature that identifies ethical issues that may arise from conducting CBPR studies, and the recommendations by researchers to mitigate such challenges. Keywords CBPR, Qualitative Research, Ethical Issues*

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### Introduction

Community-based participatory research (CBPR) is a methodology increasingly used within the social sciences (Banks et al., 2013). CBPR emerged in the 1970s, in concert with critical theories and social change movements, all of which started to influence knowledge building in the social sciences (Healy, 2001). According to Minkler (2004), CBPR is a methodology that is heavily influenced by the theoretical bases of Kurt Lewin's (1948) theory of action, Paulo Freire's (1970) critical pedagogy, and other third world scholars whose aim was to develop "revolutionary approaches to inquiry as a direct counter to the often "colonizing" nature of research to which oppressed communities were subjected" (p. 686). Lewin's (1948) theory of action emphasizes "the active involvement in the research of those affected by the problem under study through a cyclical process of fact-finding, action, and reflection, leading to further inquiry and action for change" (Minkler, 2004, p. 686). Freire's (1970) critical pedagogy accentuates *Conscientização*, which he theorized was the first step of

"praxis," or the action of the oppressed to take action against oppression. Praxis at the collective level produces social transformation (Freire, 1970).

CBPR is an umbrella term that encompasses a variety of research methodologies, including participatory research, participatory action research, feminist participatory research, action research, and collaborative inquiry (Minkler, 2004). At its core, they share five key attributes: (i) community as a unit of identity; (ii) an approach for the vulnerable and marginalized; (iii) collaboration and equal partnership throughout the entire research process; (iv) an emergent, flexible, and iterative process; and (v) the research process is geared toward social action.

CBPR is an approach that is widely endorsed among social work researchers, as it is aligned with the profession's core mission, values, and principles namely, the pursuit of social justice, self-determination, empowerment, and capacity building, amongst others (Branom, 2012). CBPR, proposed as an alternative to traditional top-down methodologies, is often heralded as a transformative grass-roots approach to research that can facilitate social change particularly for disadvantaged groups and communities (Branom, 2012).

While there is no shortage of literature that highlights the benefits and potential of CBPR, relatively little discussion exists on the ethical issues associated with the methodology (Mikesell, Bromley, & Khodyakov, 2013). In particular, current gaps within the literature include ethical guidance in (i) balancing community values, needs, and identity with those of the individual; (ii) negotiating power dynamics and relationships; (iii) working with stigmatized populations; (iv) negotiating conflicting ethical requirements and expectations from Institutional Review Boards (IRBs); and (v) facilitating social action emerging from the findings. For CBPR's commendable goals and potential to be realized, it is necessary to have a more fulsome discussion of the ethical issues encountered while implementing a CBPR study (Nygreen, 2009). Further, a lack of awareness and critical reflection on such ethical considerations may perpetuate the very same problems this methodology seeks to address, namely, inequality, oppression, and marginalization.

The purpose of this article is to provide a narrative review of the literature that identifies ethical issues that may arise from conducting CBPR studies, and the recommendations by researchers to mitigate such challenges. Before presenting the methods, findings, and discussion, we situate ourselves within this topic, by providing a brief overview of our backgrounds, interests in the topic, and our investments and intentions for this paper.

### **Backgrounds of Authors**

#### **Crystal Kwan**

I am a PhD candidate at the Faculty of Social Work, University of Calgary. My research interests and experiences include a variety of topics within social work, specifically: gerontology and social work, community and international development, social and public policy, and green/environmental social work. Within each of these areas, my approach to inquiry is more qualitative and participatory based (specifically, utilizing CBPR approaches). My interests in CBPR studies emerged during my Masters of Social Work (MSW) program. I enrolled in a course-based MSW program, because I initially had no interests in research (nor did I believe I had an aptitude for it). Then, I was introduced to participatory methodologies (such as CBPR) during a mandatory research course, and my perspective of research and its possibilities changed. I embarked on a research based practicum for my final year, and facilitated a CBPR study where I collaborated with eight local elders in the Philippines to explore their perspectives of community organizing (Kwan & Walsh, 2013). It was during this time that I experienced the disconnect between the ideals and theories of CBPR and the actual

practice of the approach. Still, for my doctoral study, I continued to adopt a CBPR approach to inquiry, but I wanted to ensure I re-approached the literature with a more critical lens and understanding of CBPR and its potential, limitations, and risks, and especially the ethical implications that may arise. This paper is a result of that endeavor. Initially, the purpose of the paper was to better equip myself to navigate potential ethical issues that may arise whilst conducting a CBPR study. However, my investment and intentions of this paper, now, are also to contribute to a balanced scholarly discussion on CBPR that highlight its limitations (e.g., potential ethical implications) along with its potential. Such a balanced discussion is necessary, in order for novice researchers (like myself) to be better equipped to facilitate a CBPR study and for the approach itself to become a more accepted form of scholarly inquiry.

### **Christine A. Walsh**

I am a Professor and Associate Dean (Research and Partnerships), Faculty of Social Work, University of Calgary. In my program of research, I use art-informed, action-oriented and community-based research methods to collaborate with vulnerable and marginalized populations including: those impacted by trauma, homelessness and poverty, immigrants, older adults, those involved in the justice system and Indigenous People. My research aims to improve the lives and enhance social justice for disadvantaged populations. I am particularly interested in examining the tensions between how participatory research is assessed by Institutional Review Boards (IRBs), described in the literature, and unfolds in the field.

### **Methods**

We chose a narrative literature review as it can “serve to provoke thought and controversy” and thus “may be an excellent venue for presenting philosophical perspectives in a balanced manner” (Green, Johnson & Adams, 2001, p. 103). In July 2017, we conducted a review in three databases: Social Services Abstract, Social Work Abstracts, and SocINDEX with full text. We searched the databases for instances of community-based participatory research (and variations of the term: CBPR, participatory research, participatory action research, feminist participatory research, action research, and collaborative inquiry) and ethics (and variations of the term: ethical considerations, ethical challenges, ethical dilemmas, and ethical issues) in the abstract. Additional criteria were that the articles were in English and published between January 2000 to July 2017. The search resulted in 995 articles. We removed the duplicates, and then scanned the abstracts for relevancy. We identified the articles to be relevant if they provided a definition of CBPR (or any of its variants) and discussed the ethical issues relevant to this approach to inquiry. We did not exclude review and commentary type articles, as we felt for the purposes of this narrative review, such articles can still shed critical insight into the topic. Albeit, most of the articles were empirically grounded (e.g., based on an actual CBPR study). From scanning the abstracts, we identified 35 articles that were included in this review. To be comprehensive, we conducted a further search in Google Scholar, whereby we found an additional five articles and included them in the final review. Thus, a total of 40 articles comprised the sample included in this review section.

We analyzed each article, by first reading the entirety of its contents and noting general comments about the article related to the topic (ethical issues whilst conducting CBPR). Then, upon the second reading, we extracted specific data (and inputted it into an excel spreadsheet) which included: descriptive characteristics of the study (namely, the author(s) name(s), year of publication, and type of article) and quotes or statements regarding how CBPR is conceptualized and ethical issues that arise from using this approach to inquiry. To synthesize the articles, we utilized a qualitative approach (Weeks & Strudsholm, 2008) to theme the data,

whereby similar findings were grouped together and then labelled as a category. This process of analysis also allowed us to see what was missing or not being discussed in the literature (related to ethical issues when conducting CBPR studies). To ensure reliability of the analysis and synthesis of the findings, both of us reviewed and approved the findings and categories/themes. In the next section, we present and discuss the findings of our review.

## **Discussion**

### **Unique Attributes of CBPR**

As a research methodology, CBPR espouses a unique set of values and principles (that differ from more traditional approaches) that guide the processes of investigation within a study (Healy, 2001). It is important to note that CBPR shares similar ethical considerations that arise from more traditional methodologies. For instance, the “overall harms and benefits of research, the rights of participants to information, privacy and anonymity, and the responsibilities of the researcher to act with integrity” (Banks et al., 2013, p. 266). However, the focus of this article is to tease out the ethical considerations that are unique to CBPR. Thus, we discuss five key attributes of CBPR that are identified within the literature: (i) community as a unit of identity; (ii) an approach for the vulnerable and marginalized; (iii) collaboration and equal partnership throughout the entire research process; (iv) an emergent, flexible, and iterative process; and (v) the research process is geared toward social action. For each attribute, we discuss the various ethical issues that may arise and the correlate considerations, strategies or actions recommended by researchers to mitigate such challenges. At the end of the article, we provide a table that summarizes the discussion.

### **Attribute I. Community as a Unit of Identity**

Eighteen articles included this attribute within their definition of CBPR, but only 10 articles discussed the ethical implications that may arise from this attribute. Within CBPR studies the primary unit(s) are communities of identity, whereby a community can be bound by geography (e.g., a neighbourhood), by shared identities that are socially constructed (e.g., ethnicity, age, gender, ability, or sexual orientation), or by shared values, norms, and interests (Carter, Banks, Armstrong, Kinson, & Burkett, 2013). CBPR is about knowledge building and enhancing a sense of collective identity and community throughout a collective engagement. Further, CBPR is also a political program, whereby one of the end goals is to effect social change via the collective (Healy, 2001). Working toward this goal entails capturing and detailing a group's or community's collective identity, problems, issues, strengths, and opportunities. Fostering collective identity can build social cohesion and community capacity. No doubt these are important outcomes. However, one must be cautious that in the pursuit of unity, they do not fall into the perils of essentialism and identity politics.

**Ethical issue: Contributing to essentialism and identity politics.** Essentialism and identity politics occurs when a group is ascribed a fixed and myopic identity with presumed core values shared by all its members (Dick, 2011). Such depictions of a group become problematic because “they fail to recognize that identities are social constructed and hence open to challenge and revision [and] they fail to account for the fact that individuals belong to more than one identity category, making identities complex, multiple, and contradictory, and ensuring that the experiences of group members are varied rather than uniform” (p. 30). In the face of essentialism and identity politics, marginalization can occur for those members who may have life experiences that do not reflect those of the wider group. In this way, paradoxically, CBPR’s quest toward collective identity and unity can potentially impose on or

exclude individual community members – disempowering the individual's ability to self-determine and self-identify (Healy, 2001).

To mitigate this ethical risk, Dick (2011) suggests adopting an anti-essentialist approach to collective identity, such that identities are contingent, contextually situated, and are always in construction. Further, identities, she noted, “are the product of both assignment and choice; they are something for which affirmation is sought, yet they are also the subject of deconstruction, negotiation, challenge, resistance, and revision” (p. 32). CBPR, which is praised for its democratic process to knowledge building, is often depoliticized and the political conditions of researchers and participant researchers are seemingly forgotten (Gauchet, Manent, Finkelkraut, Seaton, & Mahoney, 2004). Gauchet and colleagues (2004) posit that “every governing of a collectivity by itself implies a certain number of constraints weighing on individual rights and identity” (p. 153). It is pertinent, then, that efforts to build collective identity and voice within a CBPR study, do not at the same time silence the individual differences among community members.

## **Attribute II. An Approach for the Vulnerable and Marginalized**

Thirty articles included this attribute when conceptualizing CBPR, seven of which integrated a discussion on the ethical risks and implications that may arise due to this attribute. CBPR is an approach that is often used to give voice to vulnerable and marginalized communities (Wahab, 2003). Underpinning CBPR methodologies is the “commitment to accessing voice and to creating spaces for these voices to be heard” (Bradbury-Jones & Taylor, 2015, p. 162). The idea is for those who are directly affected by social inequalities and injustices to construct their own stories and identities to avoid “a portrayal of the participants as they are constructed in dominant ideology” (Coy, 2006, p. 428). While CBPR can facilitate the deconstruction of social stigmas attached to groups and communities, it can paradoxically reify the same negative perceptions (Joanou, 2009).

**Ethical issue: Risk of re-stigmatization, two case examples.** Re-stigmatization occurs when the narrative of negative stereotypes, perceptions, and assumptions about a particular group or community is being supported and continues to persist within new contexts (Joanou, 2009). Walsh, Hewson, Shier, and Morales (2008) highlight the risk of re-stigmatization through their PAR study with youth in a geographic community that was dominated by negative perceptions and stereotypes. The initial focus of the study was to engage youth to document through photography and group dialogue a “problem or area for change in the youth’s community and facilitate a youth engagement project that addressed this concern” (p. 385). This research agenda was challenged by one of the youth participants, who questioned the need for their community to be fixed and singled out, noting that other communities experienced similar problems (e.g., violence and crime). They explained that:

This concern about further stigmatization shifted the focus of the project resulting in the youth taking pictures of what they considered to be the positive and negative aspects of their neighborhood and reflecting on both dimensions. While the project the youth engaged in focused on an area for change, the images exhibit they presented to the community represented a balanced view of their neighborhood. (p. 385)

To mitigate the potential harm of re-stigmatization, they recommend that the focus of research programs should not be determined primarily by the negative perceptions and stereotypes of the stigmatized community or group. Although they note, labels such as “at-risk” youth or “disadvantaged” communities do “place emphasis on the need to invest in research funding in

this area” (p. 386). In this situation, the research team was faced with an ethical dilemma and had to consider whether the risks of identifying the community as disadvantaged outweighed the “possible positive outcomes experienced by the participants and the wider community” (p. 385).

In contrast to Walsh and colleagues’ (2008) experience, Gubrium, Hill, and Flicker’s (2014) CBPR study highlights the potential of participant researchers, themselves, re-stigmatizing members of their community. In their study with young mothers as participant researchers, the researchers were concerned:

. . . with the way, some participants reaffirmed dominant negative narratives about “teen mothers.” The workshop participants spoke of some as “greedy and lazy recipients of welfare,” “partiers” who were “bad mothers,” and their own mothers who “were not in the picture.” Although the participants themselves could be classified as teen mothers, they used derogatory language during the workshop as a way to contrast themselves with other young women (as well as their own mothers) who had not risen to the challenge, to position themselves as good mothers despite the odds. (p. 1611)

This situation raised an ethical dilemma for the researchers. On the other hand, for research purposes, this was data that could be useful to “illustrate how participants negotiated narratives on young motherhood and youth sexuality”; however, “for advocacy purposes, the stories might fail to dislodge conventional conversations” (p. 1611).

What Gubrium and colleagues (2014) did in this situation was incorporate a subsequent workshop, where “participants were asked to consider dominant representations of young mothers and youth sexuality in the mass media and then to reflect on their own stories in this regard” (p. 1611). In this workshop session, the participant researchers were challenged to think critically about their narrative representations and gently questioned by their “word choices that have the potential to reinforce negative stereotypes or place blame for systemic health problems on individuals” (p. 1611). Thus, they suggest that it is important that the narrative representations by participant researchers are paired with critical discussions to “both acknowledge external structures and discourses that shape [the participants’] perspectives and opportunities in the world to put forward a coherent alternative vision” (p. 1611).

### **Attribute III. Collaboration and Equal Partnership throughout the Entire Research**

#### ***Process***

Thirty-six articles identified this attribute as an important dimension of how CBPR is conceptualized, and all the articles discussed ethical issues that arise from this attribute. Collaboration and equal partnership between researchers and participants distinguish CBPR from other methodologies (Carter et al., 2013). Within CBPR studies, participants share equal responsibilities, decision-making power, and ownership of the research study. This equalitarian stance is a laudable aspect of CBPR, yet in practice is challenging and complex (Connolly, 2006; Gilbert, 2004; Maglajlic, 2010; Maiter, Simich, Jacobson, & Wise, 2008; Nygreen, 2009; Pyles, 2015; Riecken, Strong-Wilson, Conibear, Michel, & Riecken, 2005; Ward & Gahagan, 2010). Without careful considerations of various issues at play (e.g., power dynamics and relations, resources available, and existing competencies) there is the potential of tokenistic partnerships and “false equalitarianism” that can emerge, and as such can cause further harm to participants and the community (Nygreen, 2009, p. 19).

**Ethical issue: Underestimating the complexity of power dynamics and relations.**

Power dynamics and relations, defined as how power works in a specific context such as who has (and who does not have) the ability (or agency) to influence others, to negotiate, to affect change, and to make decisions, are intricate before, during, and after a CBPR study (Joanou, 2009). In Franks' (2011) cross-cultural CBPR with children the issues of power while at the fore, remain unresolved:

The call for participation can at times ignore the complexity of power relations not only between the adult researcher and young participant researchers but also between funding bodies, the researcher(s) and the organizations they work for and the researched . . . . A methodology that is unequivocally participatory and non-hierarchical is still to be found. (p. 16)

Nygreen (2009) reminds us, "one cannot simply follow the steps of [CBPR] and expect the problem of domination to be solved" (p. 19). There is nothing built-in the process of CBPR that can "transcend the dilemmas of power inherent in the research process" (p. 28). Further, power dynamics and relations can shift over time (Nugus, Greenfield, Travaglia, & Braithwaite, 2012).

**Ethical issues: Overlooking resources available and existing competencies.** CBPR is an approach that is often used with disadvantaged groups. Thus, a rigid focus on equal participation fails to acknowledge prior inequalities. Inequities, for example, arise from different socio-economic status, education levels, gender, sexual orientation, financial capacity, age, ability, and religion and power dynamics (Green, 2004). Also, often community members and researchers have different access to resources and skills. These fundamental inequities can potentially place unfair expectations (and additional burdens) on participant researchers. Green (2004) insightfully elaborates upon the balance of exploitation and equality of CBPR, which:

. . . 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. (p. 699)

Despite acknowledging the limits to achieving equal participation, this directive of CBPR remains relatively unchallenged within the literature and stunts necessary conversations as to how equal partnership, power, and control can be facilitated (Healy, 2001). Researchers should articulate the power dynamics and inequalities between researchers and participant researchers at the onset of the research endeavor and what efforts were undertaken to reduce them. In a fulsome accounting, researchers should acknowledge both effective and ineffective strategies and for which groups. In response to the question, if it is possible to sustain equal partnership across all aspects of the research process, Banks and colleagues (2013) conclude that "community control and equal partnership are much less common in practice than professional control with elements of community participation" (p. 265).

Morgan, Cuskelly, and Moni (2014) caution researchers, to keep in mind “while participatory research promotes partnerships, it does not necessarily emphasize equal distribution of power” (p. 1312). Thus, adequate discussions about the challenges towards achieving equal partnership are necessary to mitigate the potential harm of exploitative relationships or tokenistic partnerships (Green, 2004). For instance, Minkler (2004) suggests that the focus should be on equity rather than equality. The shift in terminology, she argues, is significant in that it implicates an analysis of the prior inequalities and power dynamics at play – not only between researchers and participant researchers but also among the participant researchers. The analysis should be ongoing, as partnerships change and evolve overtime and across different aspects of the research, so will the balance of power (Banks et al., 2013).

Further, a power-neutral approach to partnership may not be ideal (Healy, 2001). For example, within an evaluation of a PAR study she facilitated, Healy (2001) shared, that participants

commented on the positive and negative aspects of power that remained in spite of [her] commitment to reducing power differences. On the one hand, participants saw some operations of power as useful for maintaining collective cohesion and direction amongst participants. On the other hand, participants emphasized the power to which [she] continued to have access, such as that connected to [her] privileged educational status. (p. 97)

She ascertains that rather than assuming power-neutral positions or averting exertion of power, that we acknowledge both positive and negative operations of power, to address the negative effects and to facilitate the positive effects. She warns that a power averse or power-neutral approach does not make inherent power differences disappear, rather “such recognition is sent underground” (p. 97). Nugus and colleagues (2012), in a review of their CBPR study within a bureaucratic organization, affirms Healy’s (2001) re-conceptualization of power through their statement:

Participatory research needs a concept of politics and power beyond the fixed oppositional categories of empowerment and disempowerment. Power is shifting, not fixed, and a source both of opposition and opportunity. So, power relationships, such as those exposed by research, need constant critical reflection. (p. 1951)

Wahab (2003) also highlights the need to re-conceptualize power through the commentary of her PAR study with female sex workers, by sharing her pitfalls of falling into a narrow view of power:

During my struggles with feeling like I was betraying the participants, I found myself consumed with the notion of power as “power over,” “power to dominate,” and “power to coerce and control.” I had significantly overlooked the authentic power of the study participants . . . . Once, I reconceptualized the notion of power to include “power within,” “power to create,” and “power as ability,” I was able to identify the different ways in which we all held and exercised power in the inquiry process. (p. 637)

If participant researchers are truly to be co-researchers in the CBPR process, then the roles and tasks assigned to them should be congruent with the resources available to them and their existing competencies and skills (Bergold & Thomas, 2012; Gilbert, 2004). Similar to the

discussion on inequities reference above, Bergold and Thomas (2012) note that ensuring such congruencies are often taken-for-granted and “must be called into question, because co-researchers frequently belong to lower social class or marginalized groups and have limited material resources at their disposal” (p. 201). Material resources can include direct remuneration. Professional researchers are often paid a salary for their work, and as such participant researchers cannot be expected to provide their time, knowledge and expertise for free (Bradbury-Jones & Taylor, 2015). Albeit, direct remuneration can also be tricky as it can imply commodification of the participant-researcher(s)’s knowledge (Coy, 2006). Further, Campbell and Trotter (2007) warn that simply providing a payment “would not solve any ethical dilemmas” (p. 38). Thus, it is important to consider how the payments are made and not just what the payments are (Bradbury-Jones & Taylor, 2015). Payments should not be paternalistic, and they should be considered as “ethical fair returns” for the participant researchers’ contributions to the study (p. 168). Also, context is crucial to consider regarding remuneration, as what may be considered a small amount for some can be great for others. Bergold and Thomas (2012) expand on the provision of material resources:

There is no rule about what material resources should be made available to research partners. It depends on the group in question. Resource provided could include travel expenses, childcare costs, food for participants with special dietary needs, compensation for loss of earnings, etc. (p. 201)

In addition to making specific resources available to participant researchers, it is also important that if there lacks a congruency between methods used in the study and competencies of participant researchers that comprehensive training and ongoing support is provided (Carter et al., 2013; Warr, 2011). For instance, participant researchers are often assigned to conduct interviews within their community and depending on the research topics and questions; such interviews may sometimes evoke difficult stories and discussions that can also impact the participant researchers' emotional well-being. A supportive environment is touted as a potential solution as Carter and colleagues (2013) explain:

The intensity of community-based research often necessitates formalized reflection processes where researchers cannot just reflect, but also debrief about their experiences in a supportive environment. This . . . is a critical part of a community based research project – there needs to be “community” built into the research process itself so we are not just studying the “community out there.” (pp. 99-100)

Lastly, Bergold and Thomas (2012) note that it is important to incorporate not only opportunities to develop specific skills and knowledge to conduct the research, but also “more general competencies, all of which contribute to personal development” (p. 208).

Competency building is not a one-way pursuit; CBPR studies also need to focus on the competencies of the professional researcher. For instance, Bruges and Smith (2009), in a commentary on their CBPR study on sustainable land use with Maori communities and scientists on the East Cape, New Zealand explained that their “project was also designed to improve the ability of a scientist to work with rural Maori communities . . . [by providing] both formal and informal advice and training to [the scientists] regarding Maori protocol and traditions” (p. 212). As CBPR partnerships often involve cross-cultural research; it is important that professional researchers can facilitate CBPR through an ecological approach, which involves adapting the research enterprise to the culture and context of the participant researchers (Phenice, Griffore, Hakoyama, & Silvey, 2009). While an ecological approach

includes understanding certain cultural values, traditions, and protocol, it also includes the notion of cultural humility (Minkler, 2004; Phenice et al., 2009). Minkler (2004) defines cultural humility as the idea that:

none of us can truly become “competent” in another’s culture, we can approach cross-cultural situations with a humble attitude characterized by reflection on our own biases and sources of invisible privilege, an openness to the culture and reality of others, and a willingness to listen and continually learn. (p. 691)

#### **Attribute IV. An Emergent, Flexible and Iterative Process**

Twenty-six articles included this attribute in their definition of CBPR, all of which described ethical issues that may arise from this attribute. Hugman, Bartolomei, and Pittaway (2011a) describe CBPR as an “iterative methodology in which data are generated and analysed, conclusions drawn and applied in action, the outcomes of which then become the basis for further consideration as data, . . . [and] this process can have two or more cycles” (p. 662). Further, it is an emergent and flexible process, whereby research questions, methods, objectives, and participants may shift based on the context, situations that occur, and constant negotiations between professional researchers and participant researchers (Phenice et al., 2009). This principal of CBPR aims to foster accountability mechanisms between professional researchers and participant researchers (Hugman et al., 2011a). Also, this principal encourages the voices of participant researchers to be heard and for decision-making to be shared (Ward & Gahagan, 2010). At the same time, this tenant can cause ethical dilemmas for researchers (especially university-based researchers) who are also accountable to IRBs that delineate a more procedural and linear process (Malone, Yerger, McGruder, & Froelicher, 2006; Plyes, 2015). In particular, dilemmas can arise due to divergent expectations and requirements of obtaining informed consent.

**Ethical issue: Tensions with institutional review boards.** A common requirement and expectation of the informed consent process by IRBs is that consent is provided (either verbally or written) at the beginning of any research activities with participants (Shore, 2006). Prior to giving consent, participants are to be informed about the details of the study including, for example: the purpose of the study, what they will be asked to do, what type of personal information will be collected, risks and benefits if they participate, and what happens after to the information they provide. If the individuals agree to participate then consent is provided in a formal manner, which usually involves signing a written consent form or verbally providing a statement of consent that is audio-recorded (Hugman et al., 2011a). There are advantages to this formal approach as Hugman and colleagues (2011a) note:

it is explicit, clear, can be tracked and scrutinized and in the event of a complaint can provide the basis for structured accountability. Thus, it can be said to achieve the goal of ethical accountability “being seen to be done.” (p. 659)

However, within a CBPR study the proposed research activities, timelines, and expectations of participant researchers, communities, and professional researchers likely change due to the emergent and flexible nature of the methodology. Thus, the original information provided to participants may no longer be relevant, and the ethics application will need to be modified. While this is not an issue in itself for professional researchers to submit an amendment to the IRB, it is the length of time it takes for the amendment to be reviewed and approved before any new research activities can be taken that can be problematic. Further, if the participant researchers and the community decided such actions, then it seems conflicting to the principals

and values of empowerment and shared decision making of CBPR to seek the final approval from the IRBs.

Hugman and colleagues (2011a) outline another ethical issue that arises from the formal consent procedures required by IRB:

It relies heavily on a complex approach to legal rights and obligations (and limits to these) that in turn depends on the capacity of people to exercise their rights. It assumes knowledge, confidence and other personal and social resources to understand and to be able to claim redress should the need arise. (p. 659)

As we indicated previously, CBPR studies are often facilitated with marginalized and vulnerable populations, and in certain situations, such a formal process can be “alien or intimidating, or where rights are simply impossible to enforce” (p. 660). For instance, the authors speak to this issue through their experience conducting a CBPR study with women living in an isolated refugee camp fraught with security problems. They question how informed consent can be practiced when individual autonomy, access to exercise rights and agency is precarious for potential participants. In such a situation, following the typical formal consent process as required by IRBs may “satisfy only the institutional governance systems without guaranteeing safeguards for participants” (p. 660).

Hugman and colleagues (2011a) suggest adopting a multi-fold iterative approach to informed consent, which may assist researchers in mitigating some of the ethical dilemmas related to the informed consent process. The approach they propose entails, first consent being

sought from the group . . . [and then] the next step of consent is that after a first contact the group has an opportunity to continue or to withdraw. Then, third, informal consent is obtained from individuals initially, on the basis that when they have seen how the research progresses then they will be asked to give formal consent for what has taken place to be used as data. Fourth, at a fairly late stage by comparison with orthodox practice, formal consent is sought and if given a form is signed. (p. 666)

They propose, “this process . . . constitutes a more realistic way of ensuring that consent is actually informed” (p. 666). Hwang (2013) also recommends a multi-fold approach to informed consent when working with children, whereby in her CBPR study she “asked for children’s as well as the parent’s informed consent to participate . . . at every stage” (p. 453). A multi-fold approach to consent may conflict with conventional IRB requirements. As a corrective, Hugman, Pittaway, and Bartolomei (2011b) remind us that there is “often need to negotiate and even educate those colleagues who constitute such committees about the practical realities of conducting research well in ethical terms in this type of setting” (p. 1282). Further, for researchers seeking guidance on completing an ethics application for a CBPR study, Gubrium and colleagues (2014) suggest accessing examples from The Ethics Application Repository (TEAR <http://tear.otago.ac.nz/>), which is “an online archive of IRB applications donated by international scholars” (p. 1606). Such examples may help in the negotiation process with IRB.

#### **Attribute V. Research Process Is Geared Toward Social Action**

Twenty-nine articles integrated this attribute in their conceptualization of CBPR, while 11 discussed the ethical issues that may arise from this attribute. CBPR is an action-oriented methodology, and as such, research activities include mobilizing research participants and

others to take social action based on the knowledge built throughout the research process (Minkler, 2004). Dawson and Sinwell (2012) explain that those who engage in CBPR “are social movement researchers who employ research techniques aimed at exposing social inequalities and who seek to actively promote progressive social change” (p. 178). If not critically reflected on, this aim towards social action and change can raise various ethical issues and dilemmas such as culturally inappropriate expressions of social action negative consequences for the participant researchers and the community, which is elaborated on in the next section.

**Ethical issue: Culturally inappropriate expressions of social action.** Social action is the process of facilitating change at the societal and structural level, and expressions of social action are the mediums in which the process occurs (e.g., organized protests, policy briefs, research) (Hick, 2009). CBPR’s historical origins and current renderings have been tied with social change movements, whereby expressions of social actions are often characterized by western traditions and values of “conflict, protest, and dissent” (Healy, 2001, p. 102). This approach to CBPR is based on a conflict theory of society, in which development occurs through the struggle between groups over limited resources (Stoeker, 2003). Stoeker (2003) states that through the lens of conflict theory:

Stability in society is only fleeting, and to the extent that it is achieved even temporarily, it is not because society finds equilibrium but because one group dominates the other groups. Conflict theory sees society as divided, particularly between corporations and workers, men and women, and whites and people of color. The instability inherent in such divided societies prevents elites from achieving absolute domination and provides opportunities for those on the bottom to create change through organizing for collective action and conflict. (p. 40)

CBPR as informed by conflict theory encourages expressions of social action that is more confrontational (Healy, 2001). Healy (2001) cautions, while these expressions “may be acceptable to certain population groups, such as some central and southern American culture, it cannot be assumed that these values are equally applicable to other cultural contexts” (p. 102). The ethical concern, she raises, is that while CBPR is often touted for its cross-cultural applicability, existing literature fails to acknowledge the reliance of the methodology on western-based values and traditions, and the implications of culture in shaping the research process, including the social action strategies made available to participant researchers and the community.

To mitigate the ethical risks of cultural inappropriate expressions of social action, the notions of cultural competency and humility, noted earlier in the article, should be considered. It is important that CBPR practitioners critically reflect on their social location, assumptions, biases, and values and how these impact their preferences towards different expressions of social action. What constitutes social actions must be negotiated with the participant researchers and communities and be appropriate to the cultural context.

**Ethical issue: Negative consequences of actions, two case examples.** Another ethical dilemma faced by CBPR researchers, especially relevant to studies initiated by the professional researcher(s), are the negative consequences that can ensue for participants and the communities after the action is taken. For instance, Bruges and Smith (2009) highlight this ethical dilemma well, in their commentary of facilitating sustainable land use in a CBPR study with Maori communities. The growers of the Maori communities had decided on growing organic kumara and, the scientist was enlisted to help them achieve this goal. However, after

the study was completed it gained some criticism from external actors as the authors (2009) reported:

A prominent Māori academic invited to a Crop Science for Māori hui criticised the fact that the project was focused on organic kumara production. He argued that this focus was unhelpful to Māori as it instilled unrealistic expectations in terms of the potential for kumara production as a viable land use for Māori landowners in the 21st century. Similarly, a visiting organic vegetable wholesaler confirmed that there was little demand for organic kumara, with two large-scale producers in Northland easily meeting current market requirements. (p. 216)

The response from the scientist to such criticism was that their role was to support the Maori growers to define and achieve their own community goals and that it was "not to provide comment on the economic viability of kumara production in the East Cape, a question outside their specific expertise" (p. 216). However, Bruges and Smith (2009) raise an important ethical question in this situation: "can a well-intentioned focus on the goals of the community unknowingly perpetuate the unrealistic aspirations of the community?" (p. 216).

To address this ethical dilemma, Bruges and Smith (2009) focus on the process of "informed decision-making, [whereby] scientific research should provide increased choices and awareness of the implications of these choices" (p. 217). While this process is implicit with the CBPR approach, it needs to be made explicit as there is "a danger that in trying to correct for the technocratic ideology inherent in many previous research and extension methodologies, the participatory approach might see some well-meaning practitioners overcompensate by unquestionably adhering to the goals of the client group" (p. 216).

Negative consequences of the actions taken in a CBPR study can deeply affect participant researcher(s) and communities' lives, such as their livelihoods (as indicated above) and even their safety can be compromised. Hewitt, Draper, and Ismail (2013) remind those embarking on a CBPR study that "despite its potential benefits . . . it is critical to note, however, that [such] approaches *always* [italics in original] carry risk and have the potential to be uncomfortable, even dangerous for participants as they challenge the status quo" (p. 17). For example, Dawson and Sinwell (2012) outline the ethical dilemmas they faced in a CBPR study that was linked to social change movements in South Africa, whereby participants' safety could have been compromised if the actions to "organize a united march" was initiated (p. 183). Before the desire to organize this march, the authors described two events that deterred them from pressing for the march:

First, in the community of Etwatwa, east of Johannesburg, residents held a mass meeting demanding that their local government councilor step down. The councilor called the police who then proceeded to shoot three residents with live ammunition, injuring two and killing one. This was followed by the arrest of several residents. Around the same time, another battle over electricity between middle-class residents and shack dwellers broke out in Protea South (another LPM affiliate in Soweto) and two people were shot. (p. 183)

The authors noted, "Our ability and desire to coordinate mass action, without necessarily being directly affected by the consequences of that action, raised important ethical questions . . . . [and] we must not expect poor people to fight battles for us while we decide when to be the observer and when we will be the participant observer" (p. 183).

Dawson and Sinwell's (2012) commentary on their study highlight the need for CBPR researchers to carefully reflect and consider what actions they are encouraging the participant researchers and communities to take, as in some situations such actions can lead to severe and dangerous consequences.

### Conclusion

CBPR is a "highly promising approach to community-based research and practice" with praiseworthy goals and objectives, such as social change, empowerment, and capacity building (Minkler, 2004, p. 695). It is also a difficult terrain to navigate and not immune to ethical challenges. In this article, we reviewed five key ethical concerns and the correlate suggestions to mitigate such problems regarding CBPR; the findings of which are summarized in Table 1.

Table 1.

*Summary of Community-based Participatory Research Ethical Issues and Recommendations*

| Unique Attributes of CBPR   | Ethical Issues   | Recommendations   |
|---|--|---|
| I. Community as a unit of identity  | Essentialism and identity politics   | Adopt an anti-essentialist approach   |
| II. An approach for the vulnerable and marginalized                             | Risk of re-stigmatization  | Focus of research program not to be determined solely by problems/issues of stigmatized community<br>Narrative representations by participant researchers to be paired with critical discussions              |
| III. Collaboration and equal partnership throughout the entire research process | Tokenistic partnerships and false equalitarianism<br>Nothing inherent within the CBPR process that transcends the influence of power dynamics and relations<br>Methods used are incongruent with the resources available and existing competencies | Focus on equity rather than equality<br>Focus on positive uses of power rather than adopting a power neutral and/or averse position<br>Ensure resources are provided and time availed for competency building |
| IV. An emergent, flexible and iterative process                                 | Tensions with IRB's expectations and requirements for informed consent   | Adopt a multi-fold and iterative approach to informed consent<br>Negotiate and educate IRBs<br>Use TEAR repository for examples of IRB applications of CBPR studies   |

|  |   |   |
|--|---|---|
| V. Research process is geared toward social action | Culturally inappropriate expressions of social action<br>Negative consequences for the participants and communities | Professional researcher to reflect on own social location, assumptions, biases, and values and how these impact their preferences for different social action strategies<br>Adopt a cultural humility approach towards social action strategies<br>Adopt an informed-decision making approach |
|--|---|---|

Our goal is not to deter the use of CBPR, but to contend that such ethical concerns need to be acknowledged, discussed, debated, and addressed within the literature. In failing to reflect upon these issues, they can be silenced while the positives and strengths of the CBPR methodology are hegemonic (Healy, 2001). Through a frank, reflective, and critical discussion on ethical issues unique to CBPR, researchers may be more prepared to navigate such challenges and realize the praiseworthy goals and potentials of CBPR.

When interpreting the findings of this review, there are a couple of limitations that should be considered. First, since we utilized a narrative literature review methodology, which is relatively less methodical compared to a meta-analysis or systematic literature review, we were able to include review and commentary articles. These types of articles can provide unique insights, and provoke controversy and thought regarding a discussion topic. Albeit, there are higher levels of subjectivity and biases in reviews and commentaries compared to articles based on original research, for example. Second, we only included articles written in English, and thus potentially excluding articles that may highlight additional ethical issues of conducting CBPR in different cultural contexts.

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### Article Citation

Kwan, C., & Walsh, C. A. (2018). Ethical issues in conducting community-based participatory research. *The Qualitative Report*, 23(2), 369-386. Retrieved from <http://nsuworks.nova.edu/tqr/vol23/iss2/6>

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