

Governing *Well* in Community-Based Research: Lessons from Canada's HIV Research Sector on Ethics, Publics and the Care of the Self

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In this paper, we extend Michel Foucault's final works on the 'care of the self' to an empirical examination of research practice in community-based research (CBR). We use Foucault's 'morality of behaviors' to analyze interview data from a national sample of Canadian CBR practitioners working with communities affected by HIV. Despite claims in the literature that ethics review is overly burdensome for non-traditional forms of research, our findings suggest that many researchers using CBR have an ambivalent but ultimately productive relationship with institutional research ethics review requirements. They understand and use prescribed codes, but adapt them in practice to account for the needs of participating community members, members of their research teams and the larger communities with whom they work. Complying with ethics protocols was seen as only the beginning, a minimum standard; our research suggests that the real ethical work happens in the field, where CBR practitioners encounter community members in diverse public roles and must forge ethical consensus across communities. CBR represents an ethical terrain in which practitioners challenge themselves to work differently, and as a result they care for themselves—and others—in ways that often resist the propensity for domination through public health research.

'... there are different ways to "conduct oneself" morally, different ways for the acting individual to operate, not just as an agent, but as an ethical subject of action.' (Foucault, 1985: 26)

Introduction

Three decades into the global HIV/AIDS epidemic, this complex health issue continues to raise important questions about ethics in research (Heimer, 2013). Investigations of HIV are closely linked with 'risky' practices (e.g., unprotected sex, injection drug use, etc.) and marginalized identities (e.g., gay man, sex worker). Examining these sensitive topics and affected

publics can place social science researchers in conflict with research ethics boards and institutional review boards (REB/IRBs), which tend to use biomedical conceptions of risk, harm and vulnerability (Haggerty, 2004; Schrag, 2010; van den Hoonaard, 2011). Biomedical orientations to research ethics ostensibly foster objectivity, drawing clear boundaries between researcher and researched. Yet, public health researchers are being encouraged to work more closely with

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communities to collaboratively design research and intervention protocols (Israel *et al.*, 1998; Wallerstein and Duran, 2010). Community-based research (CBR) has been described as an alternative paradigm for public health research that is both collaborative and:

‘equitably involves . . . community members, organizational representatives, and researchers in all aspects of the research process. The partners contribute “unique strengths and shared responsibilities” . . . to enhance understanding of a given phenomenon and the social and cultural dynamics of the community, and integrate the knowledge gained with action to improve the health and well-being of community members . . .’ (Israel *et al.*, 1998: 177)

Collaboration and participation may take many forms, but often involves engaging the target community to develop the research questions, consult on the most appropriate research design, possibly participate in data collection and analysis and even assume leadership roles on research teams (Travers *et al.*, 2013). The HIV sector has an especially long tradition of engaging affected communities in the development of research intended to improve prevention, care and treatment (Rhodes *et al.*, 2010). In Canada, decades of efforts from university-based researchers and affected communities have culminated in a well-established HIV/AIDS CBR movement, which is characterized by the direct involvement of communities throughout the research process (Allman *et al.*, 1997; Harris, 2006).

Despite working with community stakeholders to develop appropriate research designs and engagement protocols, existing ethics review requirements have been described as a barrier to HIV CBR (Ogden, 1999; Flicker *et al.*, 2009). Similar reports have been provided by researchers working with other communities (Cross *et al.*, 2014). Much of this literature constructs REB/IRBs as overly bureaucratic and oppressive in contrast to the emancipatory goals of community-engaged research (Malone *et al.*, 2006; Boser, 2007; Martin, 2007). Downie and Cottrell (2001: 9–10) identified the key tensions as follows: REB/IRBs are not equipped to deal with the kinds of ‘non-traditional’ methods CBR uses; the review process offers little to CBR; the process is ‘frustrating and demoralizing’, takes too long and fails to address ongoing ethical issues. That is, ethical issues in CBR often emerge slowly and reflect tensions arising from: the problematic notion of a singular ‘community’ with delegated representatives (Jewkes and Murcott, 1998; MacQueen *et al.*, 2001); questions over who has the authority to provide community consent (Macaulay *et al.*, 1998; Marshall and Rotimi, 2001); and CBR

causing conflict between community members themselves (Marshall and Rotimi, 2001; Brugge and Kole, 2003). While some have challenged this adversarial relationship (Wolf, 2010; Guta *et al.*, 2012), the literature is often focused on the review process or on a single project, and fails to theorize outwards to other research and practice contexts.

The objective of this paper is to contribute to ongoing debates about the relevance of existing ethics review requirements (for an overview see Bell and Elliott, 2014) and to explore what it means to be an ethical public health researcher. Fox (2003) has argued that collaborative research is ‘transgressive’ because it dissolves traditional boundaries between researcher/researched and research/practice to produce more ‘ethically and politically engaged research’. What it might mean to work within a transgressive research space invites further theorizing. We turn to the work of Michel Foucault (2005: 252), who framed his decades-long intellectual project as an attempt ‘to connect together the question of politics and the question of ethics’ through an analysis of power relations, governmentality (the government of self and others) and the relationship of the self to itself—the ‘care of the self’. In the following analysis, we consider the implications of reading CBR through a Foucauldian understanding of ethics, which, we argue, is consonant with the values embedded in CBR methods, and which invites further reflection on the ethical paradigms of public health ethics.

Specifically, we use the Canadian HIV CBR movement as a site to read how the care of the self offers a critical response to technologies of governance that characterize formal ethics review and public health research. Our analysis responds to Guillemin and Gillam’s (2004) call to close the perceived gulf between ‘procedural’ ethics (REB/IRB requirements) and ‘practice’ ethics (issues emerging in the field). Using interview data collected from Canadian HIV CBR practitioners, we examine the ways in which participants navigated REB/IRB requirements while trying to work equitably (e.g., sharing resources and engaging in collaborative decision-making) with affected communities. What emerges is a conception of research ethics that is relational and socially and politically aware, but which raises questions about the limits of engagement in transgressive research and what it means to be an *ethical* researcher.

Theoretical Framework

Foucault (1994: 281) was interested in ‘how the human subject fits into certain games of truth, whether they

were truth games that take the form of a science or refer to a scientific model, or truth games such as those one may encounter in institutions or practices of control'. This control is exercised through 'governmentality' (the 'conduct of conducts'), which Foucault (2007a: 108–109) described as a complex ensemble of forms of power orchestrated through 'institutions, procedures, analysis and reflections, calculations, and tactics . . .'. Foucault's writings on governmentality have inspired notable studies of intersecting mechanisms of control within medicine, public health, law, politics and civil society (Rose, 1999; Miller and Rose, 2008; Dean, 2010). Recently, governmentality has been used to examine formal ethics review requirements in modern academic institutions (Koro-Ljungberg *et al.*, 2007; Guta *et al.*, 2013b). Although Foucault's work has been criticized for presenting a totalizing experience of power, such claims tend to overlook his final writings and lectures on ethical self-formation wherein he discussed strategies for resisting governmental operations of power (O'Leary, 2002; Oksala, 2005; Faubion, 2011).

In his unconventional approach to ethics, Foucault (1985: 25–26) examined the historically shifting and contingent nature of morality, asking how and according to 'what margins of variation or transgression individuals or groups conduct themselves in reference to a prescriptive system'. Foucault (1994: 286) was especially interested in the ancient Greek approach to ethics for its concern with the problem of 'freedom', an individual's *ethos* ('a way of being and behaviors') and the ongoing work required to cultivate it into something good and beautiful. This work on the self, or 'care of the self', was in some sense an individualistic pursuit but required cultivating an awareness of one's desires to prevent the domination of others and to ensure proper relationships with oneself and with them (Foucault, 1994: 288). These *others* are encountered in the community, in civic life and through intimate relationships and friendships. 'Care of the self' was both an ethical and political practice (Infinito, 2003: 156). Foucault (1985) acknowledged that in the ancient Greek context, this represented an elitist ethic primarily concerned with male citizens and the government of women, children and slaves, but his work suggests its potential to help rethink contemporary relations and ethical practice beyond narrowly normative or prescriptive regimes. In other words, Foucault's work is a study of norms and normativity, and yet it is not normative per se—that is, it does not tell us what we ought to do, nor does it provide a prescription for ethical action. Rather, we are meant to problematize and

critique ethical action, and apply these lessons within our own particular meaning-contexts.

Recent scholarship in bioethics has considered the implications of Foucault's work for resisting prescriptive forms of ethics (Chambon and Irving, 2003; Frank and Jones, 2003; Murray, 2007). Though Foucault was not concerned with research ethics, his work has inspired critical analyses of various aspects of the review process (Bastalich, 2009; Juritzen *et al.*, 2011). Koro-Ljungberg *et al.* (2007) have read the 'care of the self' as an invitation for researchers to think differently about ethics and their responsibility to participants. They have argued that 'care of the self' offers a 'form of ethical counter discourse' capable of problematizing 'ethical hegemony and governmentally guided ethical decision making' (Koro-Ljungberg *et al.*, 2007: 1089–1090). Consequently, Foucault's 'care of the self' provides a critical framework for rethinking research ethics. Borrowing from Frank and Jones (2003: 186), the question becomes: how can researchers 'offer [their] knowledge and skills to others with the necessary requirement of entering into certain relations of power but still care for [their] own self and the self of the other?' Drawing on empirical data, this question guides our analysis of ethics and the practice of HIV CBR in Canada.

Method

The data presented in this paper were collected as part of a multi-stage Canada-wide research study about HIV CBR and ethics review. Participants were recruited from a publicly available list of recipients of the Canadian Institutes of Health Research (CIHR) operating grant program that supports HIV CBR. A purposive sampling strategy was developed to reflect both Canadian regional diversity and the priority populations identified in national policy documents (e.g., injection drug users, etc.). In total, 50 interviews were conducted with a diverse group of university-based academics, researchers housed in community organizations, clinicians and graduate students (see Table 1 for participant characteristics). These semi-structured interviews were conducted between May 2010 and July 2011. Participants were asked to reflect on their research with an attention to how their project(s) developed, the ethics review process and the actual ethical issues that emerged over the life of their project(s). Half of the interviews were conducted by telephone, and half in-person. The interviews lasted between one to three hours. Ethics review for this study was obtained from the home institutions of the research team members, and standard informed consent procedures were

Table 1. Interview Participant Characteristics ($N=51^a$)

	Total	Percent ^b
Province/Region		
British Columbia	11	22
Alberta and Prairies (Manitoba, Saskatchewan)	9	18
Ontario	20	39
Quebec	7	14
Atlantic Provinces (Nova Scotia, New Brunswick, Prince Edward Island, Newfoundland)	4	8
Professional role at time of the interview ^c		
Academics (professors/clinician scientists and post-doctoral fellows, graduate students)	36	71
Community (researchers and co-leads/designates housed in community-based organizations)	15	29

^aSome of the interviews were conducted as small group interviews at the request of the interviewees and they brought additional members of their research team.

^bMay not equal 100 per cent due to rounding.

^cMany participants identified with multiple roles (e.g., university-based researchers who described themselves as community members).

followed. Participants were thanked with a \$25 bookstore gift card.

Data Analysis

The interviews were transcribed verbatim and the data were imported into NVivo 9 qualitative data management software. The current analysis used Clarke's (2005: 55) 'situational analysis', which complements grounded theory with a Foucauldian concern for discourse and practice. In this analysis, the data were read with an attention to Foucault's writings on ethics and governmentality to identify instances of conflict between participants, key systems (ethics review, universities, etc.) and *others* (colleagues, community members, etc.). This approach made it possible to connect procedural and practice ethics to 'problematize' current conceptions of research ethics (Foucault, 1994: 114). In the excerpts presented below, participants are identified by their status at the time of the interview with an 'A' for 'academic' (university-based researchers/clinicians and graduate students) or 'C' for 'community' (conducting research in some capacity at a community-based organization). However, these labels do not necessarily reflect how participants described themselves, with some academic participants being members of the communities they researched, and some community participants having graduate training and considerable research experience. The interviews are numbered (e.g., Interview 1, 2, 3, etc.) to distinguish participants from each other.

Results

Foucault (1985: 25) examined ethics through what he termed the 'morality of behaviors': 'the manner in which [individuals] comply more or less fully with a standard of conduct'; 'the manner in which they obey or resist an interdiction or prescription'; and 'the manner in which they respect or disregard a set of values'. Foucault's framework provided a guide to organize and make sense of the data, starting with: (i) a discussion of participants' attitudes toward procedural research ethics; followed by (ii) how they moved beyond procedural ethics to ethics in practice where they encountered risk, harm and vulnerability through their interactions with various project stakeholders (e.g., community members, peer researchers and the larger community); and, finally, (iii) how they stylized themselves as certain kinds of ethical researchers by negotiating boundaries, intimacy and conflict, and challenging themselves to work differently. In a Foucauldian vein, this examination will not make claims about what should be considered ethical (what is right or wrong), but offers instead a range of creative and dynamic conceptions of ethics and strategies for community engagement used by participants despite the supposed stranglehold of formal research ethics. The tactics described here will not be acceptable to all readers, and are not intended as prescriptive; however, they demonstrate the many ways researchers conducted themselves, self-reflexively, in the work of public health research, and how they conceived, communicated and sought to

embody a particular *ēthos* in relation to themselves and with others. Following the presentation of results, we consider the theoretical implications of these findings in the discussion.

Relationship to procedural research ethics

The goal of the project for which data were collected was to examine how HIV CBR practitioners navigate the research ethics review process. Guillemin and Gillam (2004: 263) have described this process as ‘procedural ethics’ and explain that for ‘many researchers, the completion of the research ethics committee’s protocol form is a formality, a hurdle to surmount to get on and do the research’. Koro-Ljungberg *et al.* (2007: 1078) have likened REB/IRB requirements to ‘examinations’, which leave ‘researchers little to no autonomy and control over their own research’ (*ibid* 1083). However, in our study, participants described ethics review not just as a barrier, but as necessary for protecting communities. For example, this participant working in a community-based organization explained:

I see some of it as being highly bureaucratic and not really in touch with community-based research specifically and HIV specifically, and then others make perfect sense. I think [it] does need to be required because there have been some unscrupulous researchers in the past that have gone into the same population that I’m working with . . . So I’m glad that those safeguards are in place for the community members, but they do need to be a little bit more relevant to the community research that’s done nowadays. (Interview 1, C)

This university-based participant objected to ethics review as just an obstacle to be overcome:

I get very frustrated with researchers who view ethics approval as an obstacle to their work. I have *no* patience for that argument . . . that view of getting through [and] ethics as a hoop. Rather, I think, thank goodness there is at least some milestone here that’s forcing reflection on a range of ethical issues. (Interview 44, A)

Finally, another university-based participant argued that while ethics review is not always enjoyable, it is an important part of the CBR process:

I don’t know, maybe I’m different. I don’t see a problem with having to go above and beyond. I think there’s value in being forced or being asked to be reflective about what you’re doing, in terms of not harming. I mean, it’s a pain. Yes, it’s challenging, but you are being asked to

rethink or think through your processes in a way that history shows people haven’t always done. (Interview 4, A)

Beyond procedural ethics: encountering risk, harm and vulnerability

Moving beyond procedural ethics, Guillemin and Gillam (2004: 264) have defined practice ethics as ‘the ethical obligations a researcher has toward a research participant in terms of interacting with him or her in a humane, non-exploitative way while at the same time being mindful of one’s role as a researcher’. This framing of ethics recognizes the power researchers have in the research process. Participants in this study were asked to reflect on the ethical issues that emerged during their projects, and their accounts show a sophisticated engagement with risk, harm and vulnerability in relation to community members, to peer researchers and to communities as a whole.

With community members

The majority of participants in this study demonstrated sophisticated understandings of risk and harm for the community members who participated in their projects. Some, like this next university-based participant, described a duty beyond what is expected from researchers:

So for me ethics doesn’t begin when you start to write your proposal, it starts long before that. I say to students, ‘think about the person in the world that you care most about and, and pretend that that’s the person that you’re undertaking this research with, and you don’t want to harm this person, you don’t want to disrespect this person, you don’t [want] them to feel at all exploited or coerced, so you know just treat these people as though you really care about them’, and by the way, maybe you should just really care about them anyway. (Interview 12, A)

Another university-based participant described an awareness of power dynamics in recruitment and data collection with young sex workers, which had not been raised during the ethics review. Once in the field, she stopped her project and re-designed it:

Well it was very clear from the outset that, you know, if these young kids are being approached by guys who are driving up in a car rolling down the window and buying their bodies, we weren’t a hell of a lot better. We might have been asking for their minds but we were doing the equivalent of driving up in a car rolling down the window and

asking the price and so it took us a long time to figure out ways through that. (Interview 7, A)

This next community-based participant described the challenges she experienced reconciling her dual identity as a clinician and a researcher in an interaction with a young injection drug user:

I've interviewed a kid who tells me that the only person they share needles with is their mother and I think, *okay*. At the end I say, 'Listen, you shouldn't be sharing needles with anybody'. And they say, 'Well it's my mother, she's not going to hurt me. She would never hurt me'. You are in really dangerous water there. I think, 'Oh fuck'. Well, if I'm going to continue that conversation, the gloves are off—do you know what I mean? I don't want to damage that relationship, that's a really important relationship, but the question needs to be asked. Am I going to convince her not to share needles with her mother? No! But what I want to do is plant the idea that she's probably safer if she doesn't do it with anybody. (Interview 11, C)

Finally, another university-based participant who also worked with drug users reflected on the expectation to compensate people only after data collection activities: 'Is it humane to let people, you know, stick it out through a project and suffer for four hours?' (Interview 2, A).

With peers

A popular approach in HIV CBR is the use of 'peer research assistants' (PRAs), community members trained to conduct research ([Greene et al., 2009](#); [Logie et al., 2012](#)). Many participants involved community members in their research projects in advisory roles, data collection and/or as members of the research team. This next university-based participant took issue with the lack of guidance from REB/IRBs on working with PRAs:

Like I said earlier, there are so many issues that are ethical for me [but] questions around that aren't actually there. It's all about the participants, and I think when you're working with peer researchers there's nothing in that ethics application that's about the support and treatment and ethics around working with peer researchers and their experiences. For me that's central. (Interview 19, A)

The involvement of peer researchers required new ways of thinking about ethics. Another university-based participant described needing to accommodate for the realities of PRAs' lives:

I was cognizant of the fact that some of the women that we were training as research assistants were not only sex trade workers but were also drug users and perhaps were going to have a hard time meeting a schedule and showing up on time and not coming to work high, and that they may have crisis outside of that which involved, you know, going to court or something to do with their children. So we had to make a commitment to support [the PRAs] no matter what. So we did have a woman who had an issue with her partner and as a result of that she lost her child, [and] she started using drugs again. She stopped actively working but... I went to court with her a number of times. I think you're kind of obligated when you put somebody in that position to support them through the process. (Interview 8, A)

Another university-based participant echoed the above participant's sentiment by describing a situation with a PRA that challenged for her what it means to be an ethical researcher:

We had somebody who just couldn't sit still, one of our peers. I asked her [name], how are you? What do you need and are you able to be here? She said, 'I really need to get paid early'. I said, 'So are you going to come back? I have no problem doing that. I just need to know if you're going to come back'. She said, 'I'll be back'. I said, 'Will you be present? Or will you just be here?' We had a really good relationship and she said, 'No, I'll be better'. I said, 'Okay. We start at this time and if you're back, you're back. Just so you know I get where you're at. And I really am hoping you get to come back but I get it'. She went and used and came back, and she was fine for the afternoon. But she really needed to use. I'm not going to go buy it for them. I can't do that. But I will support them to do what they need to do. Later, she and I talked about it and she said it was a huge leap of faith and trust on my part, that no one had given her for a really long time, and that is why she came back. (Interview 5, A)

These kinds of 'ethically important moments' that test researchers' relationships to established norms as well as to stigmatized and illegal practices were not uncommon.

With the community as a whole

Concern was also raised about the potential for research-related harms to extend to the broader community. One university-based participant described how being an academic in her semi-rural community brought her into direct contact with people who saw her as a resource:

I don't know if you've ever been to [city] but it's very hard to be a social scientist [here] and not have those connections made for you. People walk into your office and say, 'Are you a researcher, can you help me?' And I've always thought one of the most unethical things we can say is 'no', when we're asked by marginalized groups to help them. (Interview 26, A)

This next university-based participant described wrestling with the socio-historical context that her work is part of and feeling a duty to ensure this project would be different:

We knew we were operating in a context of distrust and we felt a certain sense of, accountability isn't quite right, but we had this certain responsibility and this certain, and it's not obligation, 'cause it's not something that was we felt was a burden, but we definitely had a sense that we had to do this right, and this was our duty, this was just part of who we were and how we were going to approach this. And we wanted this project to be something that built trust that allowed for future research. (Interview 27, A)

Furthering this sentiment, this last university-based participant described her feelings of trepidation during a dissemination activity where sensitive findings were being presented back to the community, including individuals whose data were included:

We presented the findings and I was crying and I said, 'I feel like I am hurting you again, with your own words, it almost feels like I'm doing you harm by presenting these words back to you, your stories back to you', and they said, 'No, you're not hurting us, this is our story and we need to tell our story, and yes, it's painful to hear it, but it's something that needs to be told, don't feel like you're hurting us, even though you are hurting us'. (Interview 12, A)

This example raises important questions about the potential of data, interpretation and analysis to stigmatize whole communities, and the importance of an ethics of representation (Fine *et al.*, 2003). The preceding examples suggest how risk, harm and vulnerability were conceptualized to reflect a shared sense of responsibility that was conveyed by many of the researchers interviewed. They struggled with complex ethical issues that existing ethics review structures rarely consider (Flicker *et al.*, 2007). Toward finding resolutions for these ethical issues and determining how to proceed, many participants turned not to their REB/IRBs, but instead to collective decision-making structures.

Ethics as shared responsibility

A number of participants described building on the relationships they had established with participants and their academic or community partners to negotiate complex ethical issues. This university-based participant described relying on community members to tell her if she had overstepped her boundaries:

I mean there's always the worry of doing harm rather than good. I also trust the participants so much that if there's a risk, or if they're feeling uncomfortable or if there's the potential of harm, they're going to let me know, I mean these are really open forthcoming people. I mean this is why I have a lot of respect for people who use drugs regularly and who face the challenges of that because there's no pretence. It doesn't get more real than that, and I really trust them to know that, to let me know what's going on in their lives, what's going on at this particular moment, and so I'm not as tormented about the potential risk or harm. I really trust people to help me negotiate through that and to be honest about it. (Interview 26, A)

This next university-based participant described finding community-relevant solutions through dialogue with his community partners:

We feel our primary responsibility is to the community that's involved, not the institutional REB. So we try and generate solutions at the community level, and try and address those within our ethics applications. But, you know, we feel that it would be, it would be showing a lack of honouring of the community if we simply took every ethical issue to the REB and negotiated a solution with them without first generating solutions within the community that's acceptable to them. (Interview 2, A)

Community partnership as ethical terrain

An often-noted difference between CBR and traditional modes of research is a commitment to partnership building with communities (Israel *et al.*, 2001). This includes the expectation that researchers leave the 'ivory tower' and enter the community in significant ways. However, the emphasis on sustained partnerships in CBR invites questions about the boundaries between research and other interventions, the relationships that emerge as a result and the work required by the self to cultivate and maintain a corresponding ethic.

Boundary work

To examine Fox's (2003) claim about the transgressive potential of collaborative work, participants were asked to reflect on whether HIV CBR blurs boundaries between research, advocacy, intervention and community development. For many participants, this murkiness was described as a positive element and a defining characteristic of such work. For example, this university-based participant challenged whether boundaries are something to worry about:

I think for me . . . there's nothing wrong with those fuzzy lines. It's what I've been able to learn from the people, communities and agencies that I've had the privilege of working for or with. I would argue quite strongly that CBR, our research, is a form of intervention right off the bat. I think it's hard to draw finite distinctions in terms of research, advocacy, program development, because I think it's all interrelated. (Interview 3, A)

This next university-based participant promoted boundary blurring and described herself and her colleagues as 'academic activists':

I'm all for all blurring the boundaries, we like to call ourselves academic activists, we're not just doing research for research for but we're doing it for community knowledge development, we're doing it for capacity building, a lot of our results are feeding back into policy being developed in the city. I think it's a really good thing to blur the lines and sort of step out of the ivory tower as much as possible and work together. The beauty about CBR is that they're informing us and we're informing them. I can understand from funders and ethics boards [why] they don't like to see things blurred and everything should be quite siloed. I don't think that's the direction that research is going to be taking, at least with HIV research. (Interview 34, A)

Participants were asked if there could be problems associated with this blurring of boundaries. Most, like the previous participant, felt that boundary blurring was a positive aspect of their practice. However, this next university-based participant warned about the importance of not losing oneself in the process:

I think it's very difficult to separate the different domains when you engage with communities. These communities don't have these strict borderlines between the personal and professional that we tend to shape in our own professional world. I think that you have to be comfortable with that blurring and you always have to

maintain your own personal ethics with that When you're sitting around a table thinking you're going to set up a [protest action] you've got to think this through, you've got to protect your own morals and ethics. But I think building friendships in a research project is key to developing collaborative and caring spaces. (Interview 48, A)

Intimacy and conflict

The commitment to process and consensus building in CBR meant that participants spent considerable time with their research partners. This next university-based participant highlighted the importance of time spent at meetings, conferences, travelling together and sharing meals:

It sounds flippant but, if you're asking me what I learned, the core piece for me is just emphasized in a really strong way that, what you do when you work with people—you break bread with them. Most of the projects I've designed, the first thing you want to do, or close to the first you want to do, if people are just starting to work together, you get together and you have a meal and preferably alcoholic beverages, if that's appropriate for the group, right [laughs]? You get to know each other first, and it makes everything easier. And you know, you can expand that to the notion of community engagement and understanding community, etc. (Interview 39, A)

Many participants stressed the importance of contributing to the community outside of research related activities, such as this next university-based participant:

We've had a long-standing, very close, relationship. I can speak for myself and [academic collaborator], we've dedicated hundreds of hours of volunteer time with that organization, but also helping them write funding applications and the like. And we've been there a long time, so they know we're not just parachuting in and out, and I think that's what really makes it work, is the long-standing trust and relationship, and doing more than just research with them, has been really huge as well. (Interview 2, A)

Inevitably, spending extended periods of time together resulted in conflict and disappointment for some participants. This next university-based participant offered her approach, one based on humility, for managing these conflicts when they occur:

It can be extremely volatile, and that is the nature of relationships. I mean, it's not always a good

thing, but if you care about somebody, really care about them, I mean more than you care about your pride or your way, you find a way to make it work. You have some humility when you've made a mistake... it's been my experience, if you're honest with people and you are humble, it goes a long way... but you know anything that's going to be useful is going to be complicated... it's worth taking the time to do it well and to establish trust. (Interview 12, A)

Work on the self

The ability to move in community spaces and navigate the kinds of risks, harms and boundary blurring described above required participants to work on themselves in ways that challenged their expertise and sense of self:

You get trained to be the expert; you're the expert in the room. We're going to teach you, particularly in epidemiology, how to present your case, how to defend your case and to ward off opposition. So, you get trained to be the expert, you don't get trained to be the listener, it's a different position, right? (Interview 38, A)

This next community-based participant described having to 'perform' repeatedly to prove himself in community settings to earn and re-earn trust:

You have to prove yourself to people many times, and I used to hate that, and I used to blame people for that. I don't anymore. I understand it, we all have issues of trust. So, [the] fact that I walked through the door meant shit, nothing, so I walked through the door 10 times, until they received me with a hug and we talked about 'hey we have a new idea, or how can we write this proposal'. I was very lucky, but I'm also very forceful that way. I wanted to serve, and I did, so I was pretty much a politician that way. In [AIDS service organization] they're not stupid, they're like, 'Okay sure, you have a PhD, now show us what you do with that, you've got to dance, do the dance'. (Interview 17, C)

This level of engagement and commitment did not come easily for everyone. Indeed, it was a personal challenge for this next community-based participant:

No, I'm a total control freak. So I had to do a lot of self-talk and really work on my own desire to control this and make it productive and come out with a usable deliverable at the end of this. I constantly had to fight that through the entire thing,

and constantly had to remind myself that the process of what we were doing was just as valuable as what I was trying to get at. And I think that's what helped me, ultimately, to leave my own, the pre-conception of what I wanted to get from this, at the outset, and then allow the process to happen and basically throw my hands up and say, 'Okay, I'm going to record what happens and then I'll analyze it later and decide what it is that we have'. (Interview 1, C)

In ending our interview, this university-based participant emphasized the importance of the relationship between self and the 'messy' boundaries of this work:

In my perspective and my experience, CBR, because of all the different stakeholders and commitment and emotions and feelings and everything that's involved, is something that we can't get comfortable with. That we need to always say, 'I wish I could have done that better' or 'How am I going to do it differently next time?'... and we need to take the time to reflect, critically reflect, 'Oh, I fucked up but how can we move forward to develop this further?' Don't get me wrong, I love doing community-based research, I love the process of it, even all the challenges, the length of time, the second-guessing myself, the messiness, the discomfort, the questioning, all of that stuff, that's what is so amazing about it, it makes you have to think about these sort of things that not all researchers do, and I love that part of it. (Interview 19, A)

Discussion

The CBR practitioners we heard from responded to the requirements of formal research ethics in ways that showed an understanding of, but resistance to, dominant discourses within research and ethics review. For a number of the participants, the ethics review process was an opportunity for self-examination, an occasion for introspection that one conducts upon oneself, an opportunity to examine 'what one is, what one does, and what one is capable of doing' (Foucault, 1990: 68). These participants' narratives challenge traditional conceptions of autonomy and risk in research ethics, which tend to separate the researcher/researched, with examples that demonstrate interconnectedness and relationality in the research process. Traditional, and arguably narrow, conceptions of risk that frame community members as inherently vulnerable were challenged, while at the same time, participants critically interrogated issues of power in the research process and considered the implications of their research in terms of

individual and collective harm conceived of broadly. Thus, procedural research ethics was understood as the minimum standard, supplemented by many added levels of ethical awareness and sensitivity cultivated through individual and collective reflections. Some participants drew on their own experiences of being researched, others recognized the damage done by researchers like them who entered those same communities in the past, but all shared a desire to work differently. In doing so, they add an ethical imperative between risk and benefit established in research ethics codes: *care of the self*. Decisions about how to act were often made collaboratively between researchers and community partners and with a sense of shared accountability. Despite Koro-Ljungberg *et al.*'s (2007: 1088) assertion that ethics review 'removes autonomy and decreases individual responsibilities of the researchers', findings from this study show that HIV CBR practitioners are actively engaging with research ethics in creative and dynamic ways. While CBR has been described as a technique to govern communities (Guta *et al.*, 2013a; Guta *et al.*, 2014), it is also a site for resistance in which some CBR practitioners challenge accepted standards in research, ethics and community engagement.

Drawing on an ancient Greek context, Foucault (1985: 75) likened ethics to self-mastery, 'since one was expected to govern oneself in the same manner as one governed one's household and played one's role in the city'. The participants featured in this analysis challenged themselves to govern *well* not only in their research projects, but as part of a process of self-mastery that made their professional activities personal and political. Foucault's ethics relies on 'a certain attitude towards the self; an attitude which facilitates continuous critical self-transformation and which manifests in practices as diverse as [sodomasochism] or genealogical critique' (O'Leary, 2002: 140). HIV CBR is an important site to examine practices of self-transformation, as they manifest at the intersections of medical and public health knowledge production, the subjectivity of knowledge producers and users and health governance. This self-work often came in the form of refusing expectations to conduct research in particular ways, including challenging current ideas of what it means to be an ethical researcher (e.g., giving money to a participant experiencing withdrawal symptoms or accompanying a peer researcher to their court date). The lines between research and direct social work practice were blurred in many of these CBR projects. In Foucault's (1994: 256) terms, such examples are neither good nor bad, but they can be understood as 'dangerous' in their potential to

create new forms of domination, and so they invite ongoing vigilance on the part of researchers. While the literature contains much discussion about the challenges faced by CBR teams in obtaining ethics review, the success of CBR initiatives suggests they are navigating the process, but perhaps not all are equally able or willing to reflect in thoughtful and sophisticated ways about their practice in communities. What then is the role of REB/IRB, if any, in preparing researchers to navigate such a complex terrain where research becomes practice and social action? Some REB/IRBs are trying to work in better ways with researchers and their community partners, adopting a consultancy model where they exchange ideas (Guta *et al.*, 2012). However, our concern here is less about the ways REB/IRBs could or should respond, and more about how these practices might help us to re-imagine an ethics of public health in terms that are more commensurable with the stated values of CBR researchers and the communities with whom they work.

Our analysis challenges the distinction between 'ethics' as understood by traditional research ethics protocols (an epistemological project) and 'ethics' in the Foucauldian sense as the self's relationship with itself, 'the care of the self' (an ontological project); this latter invites a different kind of reflection on what it means to be an ethical researcher (Murray and Holmes, 2013). In HIV CBR, we see that that these two orientations to ethics are intertwined and complementary. Complex and competing interests circulating within the HIV CBR movement simultaneously reproduce and resist dominant ways of conducting research, questioning what it means to be ethical and re-shaping CBR practitioners' sense of self and other. Yet, this is not a fixed ethic in the sense of liberal conceptions of bioethics, which tend to imagine a rational, autonomous agent. Nor is it to shore up liberal conceptions of publics or public spheres, utopian spaces that value the participation of individuals presumed to be enlightened, free and, above all, equal. This would ignore the complex and differential relations of power that constitute communities in the real world (Guta *et al.*, 2013a; Guta *et al.*, 2014). Rather, we see ethics and care of the self as an ongoing performance through which one tries out different ways of *being* ethical (Infinito, 2003), ways that are sensitive to power dynamics and to the diverse communities of reception. In this respect, Foucault (2007b: 127) encouraged others to adopt an 'ethic of discomfort' and to 'never consent to be completely comfortable with your own certainties . . . [and] remember that, in order to give them an indispensable mobility, one must see far, but also close-up and right around oneself'. This type of

productive discomfort was apparent throughout many of these interviews. Our data highlight the ways CBR is ethically complicated in ways that existing ethics review systems cannot account for—in ways that might disturb those working with rigid conceptions of ethics—but which require ongoing discussion, debate and personal reflection.

Conclusion

The philosopher Gilles Deleuze (1988: 97) wrote that ‘in all his work Foucault seems haunted by this theme of an inside which is merely the fold of the outside, as if the ship were a folding of the sea’. While CBR might seem removed from mainstream public health research and practice, research ethics and public health ethics, it offers important insights into these larger issues—suggesting the ways that ‘public’ health ethics haunts research as a spectral and theoretical ‘outside’, while communities in practice are ‘enfolded’ in complex relations, inside and out, and therefore present unique ethical challenges for research. We might need to theorize communities and publics somewhat differently; it may be that a community is constituted, discursively and ethically, in ways that resist or even oppose the constitution of a public, in ways that do not quite conform to the ‘public’ of public health ethics. Building on Nixon (2006) and Nixon and Benatar (2011), who call for a *critical public health ethics* better attuned to issues of power, structure and history, we call for an ethics of community and a community health ethics that borrows and learns from—adopts and adapts—critical social science approaches that have greatly influenced public health (Green and Labonté, 2007). Foucault’s writings on governmentality, biopolitics and discipline have been highly influential in critical studies of public health and may be further useful in establishing new lines of inquiry that trace the relationship between power, politics and ethics in relation to both routine and exceptional situations in community health.

Bernauer and Mahon (2003: 162) have pointed out that transgressing ‘power-knowledge-subjectivity relations’ will differ between actors, but ‘an ethics of stylization invites one to engage in struggle according to one’s unique rootedness in the world and history’. While Foucault refused to tell others how to live, his work on ethics and the care of the self models a unique intellectual, political and personal *ēthos* that can inspire us to think and act differently (Cooper and Blair, 2002). The researchers who participated in this study demonstrated unique ways of reconciling their

passions, fears and discomfort, in community. Fine (2007) has argued that by theorizing about researchers’ subjectivities, individual researchers may become more aware of their effects on the research process and develop alternative ways of thinking about methodologies, analysis and intersubjective collaboration. But more than this, by theorizing and reflecting on these issues, they may push the boundaries of the researcher/researched relationship and imagine new roles for those engaged in public health research. While openly discussing strategies for counter-conduct may put some researchers at *risk* by making their practices visible, this is arguably outweighed by the possible *benefits* of others being inspired to rethink their own practices and to reimagine a research ethics in terms that would be more commensurable with the values and public health goals of the communities we serve.

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