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Community-based participatory research in a heavily researched inner city neighbourhood: Perspectives of people who use drugs on their experiences as peer researchers

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ABSTRACT

Community-based participatory research (CBPR) has become an increasingly common approach to research involving people who use(d) drugs (PWUD), who are often employed as peer researchers on these projects. This paper seeks to understand the impact of CBPR on PWUD, particularly those living in heavily researched and stigmatized neighbourhoods where CBPR projects are often located. This study draws on 14 in-depth interviews with PWUD who had previous experience as both peer researchers and research participants in CBPR projects conducted between July 2010 and February 2011. The study employed a CBPR approach in its study design, recruitment, interviewing, and analysis. Our analysis indicates that participants were supportive of CBPR in principle and described the ways in which it helped contest stigmatizing assumptions and researcher bias. Participants also reported positive personal gains from participation in CBPR projects. However, many participants had negative experiences with CBPR projects, especially when CBPR principles were implemented in a superficial or incomplete manner. Participants emphasized the importance of inclusiveness and active deconstruction of hierarchy between researchers and community members to successful CBPR among drug using populations. CBPR has been widely adopted as a research approach within marginalized communities but has often been implemented inconsistently. Still, CBPR can empower communities to contest forms of social stigma that are often reproduced through academic research on marginalized communities. Our findings describe how the benefits of CBPR are maximized when CBPR principles are consistently applied and when community-based researchers are supported in ways that reduce power hierarchies. This suggests a need for capacity building within affected communities to develop independent support, training, and grievance processes for peer researchers.

1. Introduction

Stigma is a 'fundamental cause' of health inequality (Hatzenbuehler et al., 2013) and has been shown to affect community health through multiple and inter-related pathways (Keene and Padilla, 2014). The stigma faced by people who use(d) drugs (PWUD) is particularly intense and multifaceted (Bourgois, 2009; Strathdee et al., 2012). It is driven by structural factors like the criminalization of drug use, the stigma directed towards people living with HIV/AIDS (Parker and Aggleton, 2003), and the intersecting oppression many PWUD face based on their gender (El-Bassel et al., 2010; Van Olphen et al., 2009), sexuality (Ibañez et al., 2005), ethnicity (Williams and Mohammed, 2008), and class (Bourgois, 2009). The spatial concentration of stigmatized groups, and in particular PWUD, within stigmatized 'neighborhood of relegation' (Wacquant et al., 2014) has given rise to forms of stigma, often termed socio-spatial or territorial stigma, that shape understandings of these neighbourhoods and follow residents even when they seek to leave (Takahashi, 1997; Wacquant, 2016, p.1273). Research has shown that socio-spatial stigma is a social determinant of health (Keene and Padilla, 2014) that contributes to, and is

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reinforced by, the concentration of socially marginalized groups (e.g., PWUD) in these neighbourhoods (McNeil et al., 2015).

In many cities, such neighbourhoods are the site of significant health inequities (Roux, 2001; Keene and Padilla, 2014), including heightened rates of HIV/AIDS infection (Hixson et al., 2011) and elevated risk of pre-mature mortality (Cohen et al., 2003). These areas are also the subject of considerable academic research (Neal et al., 2016). The academic gaze cast on areas of concentrated inequality can intensify the socio-spatial stigma directed toward people living within these areas (Wacquant, 2009) while also leading to ‘research fatigue’ among community members (Clark, 2008; Neal et al., 2016). Over the past fifteen years, researchers have increasingly responded to these concerns through research integrating principles of community-based participatory research (CBPR), a shift in research praxis that has given rise to new forms of community engagement in research processes (Minkler, 2005; Minkler and Wallerstein, 2010; Guta et al., 2014). In particular, the participation of people from heavily researched communities, including PWUD, as ‘peer researchers’ working closely with academics within CBPR projects has created new opportunities within marginalized neighborhoods that carry with them potential benefits, risks, and ethical dilemmas.

CBPR emerged from grassroots organizing against unaccountable and stigmatizing research of marginalized groups (Minkler, 2005). PWUD organized along with other groups around the world (e.g., people living with HIV) under the banner of ‘Nothing About Us Without Us’ in a political movement that resulted in widespread changes to research praxis (Travers et al., 2008). This movement fought for the emancipatory involvement of marginalized and stigmatized people in the research process (Canadian HIV/AIDS Legal Network, 2006; UNAIDS, 1999). This movement demanded the creation of programming and supports, “in fighting the fear, shame and stigma that keep us from fully participating in our communities and from accessing health services” (Canadian HIV/AIDS Legal Network, 2006, p.22). CBPR methods have been increasingly adopted in research with diverse groups, including PWUD (Souleymanov et al., 2016), men who have sex with men (Rhodes et al., 2011), people living with HIV/AIDS (Guta et al., 2014), and survivors of domestic violence (Malpass et al., 2016).

In practice, CBPR projects reflect diverse interpretations about what meaningful community involvement looks like (Israel et al., 2012). Community involvement in CBPR projects can take on a number of forms including in community review panels, advisory groups, and as peer researchers. As CBPR methods have become increasingly common and better funded, a growing number of projects have adopted a peer research approach (Guta et al., 2013). The use of peer researchers is often positioned as highly participatory and typically involves employing community members directly in the research process as members of the research team (Greene et al., 2009). Past research on peer researchers' experience documented how this kind of involvement can sometimes be disempowering (Boyd, 2008; Guta et al., 2013), such as when peer researchers are underpaid, lack opportunities for advancement, or are disciplined for failing to meet program expectations. For example, Boyd (2008) has described how participants have felt excluded and fetishized by academic researchers, and cautioned that CBPR can make power differentials between peer and academic researchers more visible. Given the increasingly large footprint that CBPR projects have within areas of concentrated poverty, there is a need for research exploring how peer researchers experience their participation in CBPR projects in order to best navigate power differentials and secure the most benefit from CBPR methods for heavily researched communities. While CBPR methods are a promising, evidenced-based approach to research (Viswanathan et al., 2004), key concepts within CBPR, like ‘meaningful involvement’ and ‘community participation’ may be applied in varying ways and translate differently within urban areas facing intense socio-economic marginalization and territorial stigmatization.

As one of the most heavily researched communities in the world, Vancouver, Canada's Downtown Eastside neighbourhood affords a unique opportunity to document and understand how CBPR methods work within heavily researched communities (Boyd, 2008; Boyd and Kerr, 2016). The Downtown Eastside is a low-income neighbourhood that is the site of Canada's largest street-based drug scene. The neighbourhood is known for its pioneering harm reduction initiatives, cutting edge addictions research, as well as high rates of poverty, unemployment, and entrenched drug use (McNeil et al., 2015). The Downtown Eastside is frequently stigmatized in journalistic, governmental, and academic discourse (Liu and Blomley, 2013; Boyd and Kerr, 2016). Here, research studies are so commonplace that participation in research has been positioned as a viable income generation strategy for PWUD (Collins et al., 2017). Filling out questionnaires, providing blood samples, and participating in interviews and clinical trials figure in alongside street vending, panhandling, and binning as a supplemental income source to offset stagnating social assistance rates (DeBeck et al., 2011). Vancouver's Downtown Eastside, the site of some of the earliest and most effective advocacy around the “Nothing About Us Without Us” principles (Boyd et al., 2009), now offers a unique opportunity to study how peer researchers experience participation within CBPR projects and their perspective on the impact that CBPR methods have had on the intense stigma and socio-economic marginalization faced by their community (Boyd and Kerr, 2016; Collins et al., 2016).

Here, we seek to add to the research literature on CBPR by drawing on the expertise of community-based ‘peer researchers’ with CBPR experience who live in the Downtown Eastside. We explore how some projects have successfully navigated the complex power dynamics between PWUD and academic researchers in a research setting. We document how PWUD have experienced the proliferation of CBPR projects in the Downtown Eastside, as well as the promises and pitfalls of CBPR to upset the intense social stigma faced by PWUD living in areas of concentrated poverty. We seek to broaden understanding of how CBPR functions within a heavily researched and marginalized community.

2. Methods

This project took a qualitative, CBPR-informed approach. This was operationalized by meaningfully involving members of the affected community in the research process from the development of the study objectives through to the analysis, interpretation, and publication of research findings. The study emerged from our established research partnership with the Vancouver Area Network of Drug Users (VANDU), a democratically-governed and peer-driven drug user organization (Kerr et al., 2006), and was developed in consultation with the organization's Board of Directors. Fourteen in-depth qualitative interviews were conducted in collaboration with a peer researcher recruited from among the membership of VANDU. The peer researcher was selected through a low-threshold four week long hiring process in which the position was posted at VANDU and interested persons were invited to fill out a simplified application form. Three members of the VANDU Board of Directors then interviewed all applicants and selected the most suitable candidate. Only one peer researcher was hired because of the scope and targeted nature of data collection and analysis activities. The peer researcher collaborated with the research team throughout the research process, from study design to data collection, analysis, and the interpretation of findings. The peer researcher also informed the content of this manuscript and provided substantive feedback on draft versions. The peer researcher was compensated at the rate of $7/hr. This hourly rate was selected by the VANDU Board of Directors and was consistent with the compensation structure used by VANDU for stipendiary volunteering positions within the organization at that time. This decision was made to ensure that compensation for individuals through VANDU-related project remained consistent to promote fairness among members participating in the organization's activities. This project received ethical approval from the Providence Healthcare/University of British Columbia Research Ethics Board.

Participant recruitment took place at the same time as the interviews and involved contacting individuals who had served as peer researchers for studies that were undertaken in Vancouver's Downtown Eastside and involved PWUD, specifically: the Community Health and Safety Evaluation (CHASE) Project (CHASE Project Team., 2005; Grebely et al., 2011); the MAKA Project Partnership (Shannon et al., 2007); the Safer Crack Use, Outreach, Research, and Education (SCORE) Project (Bungay et al., 2010); the VANDU Women's Clinic Action Research for Empowerment Study (VANDU Women CARE Team., 2009); the Injection Support Team Evaluation (Small et al., 2012); and, an evaluation of mental health and addiction services initiated by the City of Vancouver. VANDU's Board of Directors helped to identify the CBPR studies from which participants would be sampled, and also contributed to the development of the interview guide. All studies were related to the field of public health and focused on the experiences of people who use drugs and sex workers. Because these studies were oriented toward developing evidence to inform public health policy and practice, it is worth noting that they might be distinct from other forms of academic research. Once identified, researchers involved with these projects were contacted to obtain the names and contact information of peer researchers. We then contacted these peer researchers via telephone or by leaving messages through their social networks in the community to invite them to participate in our study. We aimed to and were successful in recruiting at least two individuals from each of these projects and attempted to reflect the gender and racial diversity of the local drug-using population (see demographics in Table 1). There were no refusals to participate and no one dropped out during the interview process. However, some peer researchers did not respond to messages that were left for them.

In total, in-depth interviews were conducted with 14 peer researchers between July 2010 and February 2011. All interviews were co-facilitated by a team member (CC) and peer researcher (LW) and lasted between 20 and 75 min. Interviews were facilitated using a semi-structured interview guide developed by our team (inclusive of the peer researcher). This interview guide sought to facilitate discussion of: general perceptions regarding CBPR; experiences, roles, and responsibilities with CBPR projects; perspectives regarding the development, implementation, and outcomes of specific CBPR projects. Given that participants had experience in numerous traditional and CBPR studies, they were also asked to compare and contrast their experiences across individual projects and types of research (i.e., participatory and non-participatory). All participants provided written informed consent prior to their interviews and each received a $20 honorarium following the completion of their interview. Interviews were audio-recorded and transcribed verbatim by professional transcriptionists.

Table 1
Participant demographics.

	Qualitative Interview Participants
Total Number	14
Median Age (range)	47.9 (37–58)
Gender	
Women, n (%)	6 (43%)
Men, n (%)	7 (50%)
Transgender, n (%)	1 (7%)
Ethnicity	
White, n (%)	6 (43%)
Aboriginal, n (%)	5 (36%)
Black, n (%)	3 (21%)

We analysed data by drawing on constant comparative methods during which members of our team and the peer researcher (LW) analysed data through a process of open coding and theoretical memoing. A coding framework comprised of inductive codes was developed during coding, and refined through the process of comparing and contrasting participant perspectives and experiences. Upon completion of coding and finalization of the coding framework, data were re-coded to enhance the trustworthiness of these categories (Corbin and Strauss, 2014; Glaser and Strauss, 1967). Furthermore, themes were shared and discussed by all research team members during meetings to improve the accuracy of interpretations. This study received was granted ethical approval from the University of British Columbia/Providence Health Care Research Ethics Board.

3. Results

3.1. Value of CBPR

Participants consistently expressed support for CBPR methods in principle, viewing them as necessary and important in ensuring the validity of research and guarding against the potential exploitation and misrepresentation of PWUD and the Downtown Eastside neighbourhood during the research process. Participants commonly emphasized the importance of CBPR in the context of the Downtown Eastside being a heavily research neighbourhood. Among participants, the difference between participatory and non-participatory research projects was considered like "*night and day*" in terms of participants' overall sense of satisfaction and trust in the research. Rather than implying a strict binary between participatory and non-participatory projects, as participants situated even participatory projects along a continuum, participants sought to draw attention to the critical contributions of peers to the research process. In many cases, participants expressed their value through explicit discussion of peer contributions to data collection:

> *When there's more community involvement, you get richer data … 'Cause, when I look at some of these questions, it's like, "Who the hell did this?" You know, the questions I think they should ask, they weren't asking. When you involve people in the community, they will ask those questions and you get more information.* (Participant #10, Man)

As outlined elsewhere in the literature on peer research roles among PWUD (Hammersley and Dalgarno, 2013), participants believed that they were positioned to assist with the collection of more appropriate and accurate data.

Notably, participants reaffirmed the benefits attributed to CBPR principles, such as community empowerment, improved accuracy in research reporting, and reduced negative, biases against heavily researched groups and neighbourhoods in study findings (Israel et al., 2012). Within participant accounts, bringing members of Downtown Eastside (among other heavily researched neighbourhoods) and stigmatized groups more directly into the research process was identified as a pre-condition for more effective and equitable research on their experiences:

> *To cure a neighborhood, you have to invite the participants in the neighborhood in. To think that you can solve problems by bringing people from the outside, no matter how well they're academically trained, to solve the problems is foolish* (Participant #5, Man, White)

As this quote suggests, peer researchers were supportive of the motivation to research their neighborhood and shared a sense of a need to "heal" their community but saw CBPR principles as a necessary starting point for this work.

3.2. Peer researchers and social stigma

Peer researchers were seen as able to develop a better rapport with research participants due to their shared life experiences as people living in the Downtown Eastside, and familiarity with social norms. Peer researchers' social proximity to participants was considered to help mediate the distorting effects of stigma, thereby eliciting more honest and detailed responses. Participants expressed that interviewees would be more likely to open up and speak truthfully about their experiences when interviewed by peer researchers using data collection tools vetted by community members and for projects with community buy-in. In the words of one participant, "*Even amongst people on the street who don't trust each other* – [who] *don't even like each other – there's that trust already 'cause we're one of us*" (Participant #5, Man, White).

The ability of peer researchers to build rapport in an interview was perceived as important in correcting misperceptions that many researchers were described as bringing with them to research in the Downtown Eastside. These included misperceptions that Downtown Eastside residents were somehow fundamentally "*different*" and an underappreciation of the significance of seemingly minor aspects of harm reduction programming (e.g., low-threshold harm reduction supply distribution, peer-based relationship building). One participant described this dynamic:

> *They'd only have questions that come out of books. It's like the wrong way to put it* [i.e., questions]. *They wouldn't have the right way to ask us some other question and they'd probably get just a basic short answer instead of how you and me just started going off.* (Participant #5, Man, White)

Participants often emphasized that peer researchers helped to ask the "*right*" questions and elicit more fulsome responses in an interview setting, attributing this to the rapport that they believed was established through shared lived experience. While this is unlikely to account for the full complexities of research interactions, including potential concerns regarding disclosure to peers, participants indicated that the more precise data that they believed peer researchers collected was itself necessary to help correct stigmatizing representations of PWUD's experiences in the Downtown Eastside.

Given the considerable volume of stigmatizing research and media accounts about the Downtown Eastside (Boyd and Kerr, 2016), many participants saw researchers as struggling to understand community experience and subsequently ask the right kinds of questions. Participants criticized typical research perspectives as relying on limiting stereotypes:

> *When I say I live in Downtown Eastside, 'A' they think I'm a user, "B" they want to know if I have any diseases. They're the stereotype questions that people think of from the outside. Listening is one of the hardest things to do down here because a lot of people* [that] *go there* [i.e. to the Downtown Eastside] *have already formed their opinion. Just like a lot of people live down here have already formed their opinion from outsiders.* (Participant #1, Man, Black)

For this participant, the Downtown Eastside neighbourhood was best understood as a complex "*city within a city*" but one viewed through a lens of socio-spatial stigma that led outsiders to focus only on stigmatized identities linked to health (e.g., HIV status), socio-economic status, and drug use. This illustrates how the explicit focus on stigmatizing identities at the expense of other topics reflects socio-spatial stigma, and can become embedded within practices (e.g., research questions) central to the research process.

According to participants, the kind of judgment that comes from not listening affects both researchers and neighbourhood residents. These views describe how research that does not involve community participation can reproduce and exacerbate the socio-spatial stigma experienced by those in hyper-researched community, with research questions framing, sometimes subtly, residents of these communities by stigmatizing stereotypes. The "*night and day*" difference that participants described above points to the stigmatizing potential of research as usual, with CBPR methods offering a possible alternative by providing peer researchers with opportunities to contest such socio-spatial stigmatization by attempting to align research with community priorities.

3.3. Exploitation, research, and subsistence

Participants expressed that, in retrospect, research not grounded in CBPR could potentially be exploitative and risked leveraging the socio-economic marginalization of PWUD for the personal benefit of the researchers and, in some cases, to further agendas possibly counter to the welfare of the neighbourhood and its residents. Because many people living in the Downtown Eastside live in poverty, participants expressed that it can prove difficult to refuse to participate in a research projects on ethical grounds. This can lead individuals to participate in research offering stipends even when they are concerned that it might negatively affect community members and contribute to stigmatization. As the following exchange illustrates, participants expressed anger and resentment at research that seemed disconnected and unaccountable to community interests.

> Interviewer: *What does community-based research mean to you?*
>
> Participant: *I think it's really important. I've been involved in a lot of interviews on the other side of the table where I was not giving interviews. You know, I really felt like, when I look back now anyways, I really think we were taken advantage of, you know.* (Participant #12, Woman, White)

This participant's response echoes a common feeling of exploitation expressed by study participants in relation to research projects. That is, researchers unaccountable to the neighbourhood and its residents were seen as cynically building careers on the social suffering of the community without translating research into material improvements. While most respondents acknowledged some degree of nuance to this view, notably when describing the positive changes that followed from their participation in a CBPR project, the view that researchers lacked community accountability was commonly expressed. For example:

> *I remember last Christmas … There was a guy in front of the Bottle Depot asking people to tell if they were long-term drug users for a forty-dollar survey … And he asked them about five questions, gave them forty bucks, and that was it. In and out … I never saw him again. Nobody has … People take his money anyway, right. Who knows what they want to use [the information for]? They could use the information, like, twist it against us or they could take and use it the wrong way … I mean, I would've took his money but I still*

> *would've wanted to ask him what he was doing here.* (Participant #2, Man, White)

This exchange illustrates another concern of participants about ‘research as usual’ — that is, the possibility that research would be unaccountable, non-transparent, and that results might be used in a way that would ultimately disadvantage their community.

In contrast, CBPR was positioned as potentially facilitating ‘deeper listening’ between community members and outsiders by fostering research processes that moved beyond stigmatizing categories and labels. While participants were clear that CBPR was by no means a guarantee of a more positive research experience, respondents articulated a clear preference for CBPR methods. Peer researchers' dual membership across both groups allowed them to translate research findings to their communities and neighbourhood, and to help academic researchers better interpret their findings. For example, participants, and in particular women, described more ‘democratic’ research experiences through which “*our voices* [were] *being heard and not the researchers*"” (Participant #6, Woman, White). Upon further questioning, participants described how research began to feel more democratic and thus meaningful:

> *When the researcher realized, ‘Oh,* [I've] *never thought of that.’ They were learning as well and I thought, ‘This person actually listened to me.’ I could see change. I could see that he or she is taking interest in what we're saying. It's not guaranteed change but they're gonna do their best* [right] *which makes a big difference.* (Participant #1, Black Man)

As this excerpt illustrates, CBPR began to feel more democratic when peer researchers gradually saw their contributions to projects and that they could change minds and help their academic collaborators generate new insights that better reflected community experience. In these cases, participant derived personal meaning from the projects because their contributions were outwardly valued and validated through research processes and outputs.

Among women participating in this project, this dynamic made them feel listened to in ways that made them feel safe enough to share intimate details of their life, including engagement in highly stigmatized activities, such as sex work and drug dealing. While these benefits of CBPR may, to some extent, mitigate the coercive aspects of ‘research as usual,’ they by no means completely resolve these concerns and, as outlined below, problematic practices may persist despite participatory processes (Boyd, 2008).

3.4. Pitfalls of CBPR

While participants were clear that CBPR was an important aspect of research in their community and often very positive, most participants described experiences with research projects that espoused CBPR principles but in practice failed to meaningfully involve community members. Lack of real involvement took on many forms, ranging from being asked to do unnecessary or redundant tasks, feeling judged or looked down upon by research staff, to feeling as though they had an insignificant role in the research. As one participant explained:

> *I sat at a couple of interviews and I thought well this is a waste of my time … My involvement is just … well, it would be a tick on the score sheet or a token* [role]*, if you wanna say, “Okay, we got another one.” You know, what I say really doesn't matter.* (Participant #1, Man, Black)

When asked about a particular project widely criticized by participants for its lack of inclusiveness, one participant remarked:

> *Can't remember his name* [i.e., researcher] *either … After the surveys are over, we'd send the* [participant] *to him. The guy who just finished the survey, he would go over and talk to this guy* [i.e., researcher] *and the guy would pay him and that was it. Then he just sat on the desk and just sat there right … He didn't want to be our friend but he'd talk to us … I don't even know if he was a researcher. He was just the one paying people. There was no give and take. It was just, ‘Do this.’ You know, ‘Take these questionnaires and fill ‘em out, then hand them back in.’ That was it. There was no input from us at all* (Participant #2, Man, White)

While this project provided opportunities for peer researchers to administer surveys, participants were highly critical of the power dynamics with the lead researcher. Specifically, participants expressed that they believed that the lead researcher investigator “*did not want to be close to* [them]” and that the researcher, “*just wanted their statistics or whatever information and then left*.” Among participants, this research was widely criticized for taking a “*top-down*” approach in their research and “*ordering*” participants around. Participants in such projects that did not meaningfully include them in the research process expressed frustration and resentment, feeling “*disheartened*” and seeking to “*wash their hands*” of the project. In the long run, the CBPR elements of the study backfired because of stigma reproduced through inequitable relationships between academic and community-based or peer researchers. While community members were involved, often in important tasks and throughout the research process, conflict arose because of the quality of the interactions between community and academic-based researchers. Consequently, this dynamic heightened participants' sense of being unwelcome and excluded.

Among participants, a lack of peer involvement and tension between peer and academic researchers was considered to coincide with a perceived lack of effort to translate findings into positive change within the community. In these cases, participants expressed feeling not only disconnected from the research process but also felt a divide between the goals of the larger research enterprise and need for community change to address social inequities. For example:

> *I'd seen a lot of research projects that were totally not community-based and all that did was just files* [i.e., research data] *that got put into a closet somewhere and forgotten about. Nothing was ever done about* [the findings] *and it wasn't community-based at all.* (Participant #6, Woman, White)

Projects that did not meaningfully engage community members in the research process were characterized as being primarily transactional, with little sense of connection between academics and community members, and with community members often relegated to doing simple kinds of data collection or office work. Community members felt that this arrangement reinforced a pre-existing sense of hierarchy between researchers and community members. In addition to being inconsistent with principles of CBPR, the lack of attention to hierarchy in the research relationship proved to be an important consideration that diminished participants' satisfaction with a given research project.

3.5. Hierarchy and the beneficial effects of meaningful peer involvement

Participants identified certain projects as involving them in the research process in a way that reduced, or at least helped to offset, some of the power disparities between neighbourhood residents and academic researchers. In such projects, participants described accruing considerable personal benefit through their participation, both emotionally and in terms of improved life or material circumstances. Meaningful involvement of neighbourhood residents meant more than simple inclusion and was linked to the tone and quality of interactions with researchers:

> *I think that people look at me as someone who's dependable, who's responsible and respectful to the project, right. And, I think the other thing is that because of this work ethic that I've been bringing to the whole thing it* [i.e. the project] *gives me a sense of purpose and meaning* (Male Participant #9 Man, Aboriginal)

For this participant, being seen by the research team in an empowering way was crucial to giving his involvement “a sense of purpose and meaning”. At the neighbourhood level, this suggests that CBPR is providing much needed access to opportunities locally. CBPR was described as reducing hierarchy in the research process, both between interviewers and interviewees but also between academic researchers and community-based researchers. As one participant noted, “*At first, there was a hierarchy because the researchers is like the main person* [but], *at the end, it was like everybody was at the same level*” (Participant #1, Man, Black).

Meaningful involvement in the research process was the basis for many positive outcomes of participation as community-based or peer researchers, leading to a sense of responsibility and a skill set that lead to job opportunities and other forms of professional development. For example, one participant described how their work as a community-based or peer researcher helped them change their relationship to drugs, leading to safer and more moderate drug use. Other participants expressed that they had confidence relating to others, and more comfort with the idea of working in research and other office settings. At its best, CBPR experiences were described as “*life changing*” and helping participants to “*love myself, respect myself, not hurt myself*”. For some, involvement in CBPR was an important part of larger life changes. As one respondent explained:

> *If you really look at it I probably wouldn't have my kids if … I hadn't of already been involved where I was [i.e. in the research project]. Because, at that time, I was choosing to change my life because I was becoming more and more involved in the project. And then I got pregnant and my life just kept changing. [laughter]* (Participant #12, Woman, White)

At the neighborhood level, CBPR projects provided crucial access to opportunity. Albeit short-term and not necessarily well remunerated, working on a CBPR projects represented rare opportunities for personal advancement and empowerment. Participants described CBPR projects as empowering in ways that had long-term benefits, including in relation to their identity and lower stress levels. These individual benefits extended to the community level, suggesting that CBPR can and does reduce stigma. Because many researchers bring a strong relational and anti-oppressive lens to CBPR projects, these projects offer peer researchers welcome respite from otherwise pervasive social stigma that radically shapes access to opportunity.

4. Discussion

In summary, our findings demonstrate that what CBPR means in practice can vary considerably from one project to the next, ranging from meaningful inclusion of affected communities in the study design and data collection to a research experience not far removed from underpaid ‘temp’ work. While our findings illustrate the considerable value that residents in a spatially stigmatized neighbourhood can place on CBPR methods, they also point to the potential for CBPR projects to reinforce hierarchy and reproduce stigma, especially when CBPR principles are only partially implemented. These findings align with past research raising concerns about potential ethical issues in CBPR (Boyd, 2008; Flicker et al., 2007, 2009; Guta et al., 2013; Guta et al., 2014). In the context of a heavily researched and stigmatized neighborhood, participants re-affirmed the value of CBPR, emphasizing its potential to reduce stigma by facilitating deeper listening and the reduction of researcher bias. However, within heavily researched communities, research projects would benefit from seeing themselves as already deeply embedded within community, indeed as part of a community, with the responsibilities and relational commitments those relationships entail. Unfortunately, in some cases the quality of interactions between researchers and community based peers reinforced social distance and re-affirmed hierarchy, a finding echoed in research on CBPR in other settings and with other populations (Travers et al., 2008).

Our findings underscore that participants viewed CBPR as a necessary precondition for effective research in heavily research neighbourhoods with large drug-using populations. Particularly in the context of a deeply stigmatized neighborhood like the DTES, where research is commonplace, CBPR was seen as working against negative stereotypes. In many cases, participants described deriving personal and social benefits from their involvement in CBPR, ranging from improved self-esteem, reduced drug use, to long-term employment opportunities. These findings demonstrate that CBPR can empower ‘peer’ researchers to improve their health and well being, and potentially reduce feelings of ‘research fatigue’ in heavily researched communities (Neal et al., 2016). Building on the findings of Malpass et al. (2016), participants described how their participation in the research process as peer researchers facilitated a kind of deeper listening that disrupted some of the stigmatizing potential of research. Peer researchers' mediating role in the research process has been noted before in the literature on CBPR (Israel et al., 1998; Coser et al., 2014) and reaffirms CBPR's potential to amplify marginalized voices even in heavily researched settings. These findings re-affirm the importance of CBPR methods in research and the considerable social benefit they bring to the research endeavor.

Conversely, our findings also indicate that peer researchers involved in CBPR can feel tokenized and judged when academic researchers either failed to meaningful involve peers or expressed, verbally or non-verbally, mistrust or dislike for peers. For the peer researchers we interviewed, meaningful involvement required academic researchers to learn from peers, change their minds, and actively work towards positive change in the community. These connections show how inextricably linked meaningful peer involvement, knowledge translation, and community change are. This finding highlights the potential for CBPR to reproduce stigma. As discussed in the introduction, the widespread adoption of CBPR has created new avenues for the expression and reproduction of stigma, particularly through the interaction between peer researchers and academics (Travers et al., 2008; Guta et al., 2013). As Bourdieu and Wacquant (1992) have argued, language and symbolic representations of marginalized groups reproduce stigma interpersonally and structurally. While CBPR has helped to work against stigmatizing representations by bringing peers into the research process, it has also created a new field for this kind of stigma to be expressed. As peer and academic researchers increasingly brush shoulders and collaborate, stigma can be reinforced interpersonally and at the community level as hierarchies are subtly reinforced and interviews become increasingly transactional in the absence of ‘deep listening’ and reflexivity. Whether this kind of conflict serves as an opportunity for healing and critical reflection depends on researchers willingness to embrace reflexive (Bourdieu and Wacquant, 1992) and relational (Desmond, 2014) research methods and adequate funding of community groups (Flicker at al., 2009), as mere inclusion of peers in the research process is not enough.

Our findings suggest that, as CBPR projects become increasingly common, peer researchers and others involved in CBPR (e.g., participants, community-based organizations) would benefit from independent community-based support and mentorship. Our findings echo longstanding practices in peer programming initiatives as part of service provision, where principles of reflexive learning, redressing power relationships, and developing relationships are key (Greer et al., 2016). Those charged with operationalizing CBPR would be well-served to further draw upon best practices in the delivery of peer programming toward the achievement of shared goals. Further involving peers in the leadership and decision-making for research projects will likely be necessary to this end. Existing institutional ethical review boards have been found to not adequately address the unique ethical dilemmas raised by CBPR (Flicker et al., 2007). As such, one possible way to support peer researchers would be for universities that have long-term and on-going research interests within heavily researched communities to assist community-based organizations to help support and train community based researchers, and to provide some kind of grievance process to ensure that research projects follow best practices in CBPR.

The development of a grievance process would require a community-led process and extensive consultation with affected communities regarding the composition of the relevant body, who it would represent, and how it would represent them. Existing democratically-elected drug user organizations, such as VANDU, provide excellent examples of what effective community-based governance and accountability structures might look like in this context. While acknowledging that any structure is unlikely to be fully representative due to the heterogeneity of drug-using populations, this would nonetheless represent an important step toward more equitable engagement in research processes. In the Downtown Eastside, community experience with CBPR should be harnessed and could be rewarded through the development and implementation of a CBPR governance and oversight system through the creation of a community-academic partnership involving a consortium of community groups and local universities. Given resources constraints among community service providers, university resources would likely be necessary to support such initiatives but would signal a very real commitment to the communities that they serve. Furthermore, established community-based research resources, such as the Ontario HIV Treatment Network's community-based research learning place (OHTN, 2016), could be harnessed toward the development of grievance processes for projects that fall within their mandate or where other supports do not exist.

While CBPR principles are valuable, and the increasing popularity of this approach should be celebrated, there is an urgent need to fund independent and democratically organized community groups working within heavily researched communities (Flicker et al., 2009). Importantly, this support should be independent of any particular research project. Researchers have become part of the Downtown Eastside community. Like all relationships, this is a two way street and the inconsistent implementation of CBPR principles, coupled with a lack of strong and independent community oversight of CBPR, could have long-term negative effects on the trust necessary for CBPR to function. The intense stigma faced by heavily researched communities requires multifaceted responses that work at multiple levels. As university missions become more invested in community engagement, supporting community determination and empowerment within CBPR is an obvious and necessary step forward. Public universities, in particular, should acknowledge their deep ties to heavily researched communities and take leadership in ensuring the social and economic benefits of research are captured by affected communities (Stephenson, 2010).

This study has several limitations that should be taken into consideration. First, our participants were recruited in the Downtown Eastside, a very heavily researched community where CBPR projects are common, and their experiences are likely to differ from those of individuals in other contexts where research funding differs and CBPR is less common. Furthermore, CBPR within the Downtown Eastside might have evolved differently than in other settings due to the longstanding history of social activism surrounding harm reduction and related issues. Second, this study draws on a limited number of interviews with a group of peers with varying levels of engagement with CBPR projects. Further research would benefit from focusing on the experience of women, indigenous people, the LGBTQ community, communities of color, and from community members with diverse experience in CBPR projects. Finally, we withheld some details regarding experiences with specific projects due to the need to protect participant anonymity, as providing these details risked making participants identifiable to researchers and other community members familiar with these projects.

In conclusion, while the increased implementation of a CBPR approach within areas of concentrated poverty should be welcomed it must also be accompanied by increased reflexivity with regards to research methods. It is important that research purporting to take a CBPR approach embrace all of the principles of CBR research. Our study shows it is necessary to integrate forms of reflexivity into the research process and to create opportunities for open dialogue between peers and academic researchers. Peer researchers have considerable experience with CBPR and researchers working within these communities should respect and capitalize on this fact. There is a very real risk that a lack of independent and empowered community groups could lead to CBPR being hollowed out from within, and thus perpetuating instead of challenging stigma.

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