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Between skepticism and empowerment: the experiences of peer research assistants in HIV/AIDS, housing and homelessness community-based research

Saara Greene ^{ab}; Amrita Ahluwalia ^b; James Watson ^c; Ruthann Tucker ^c; Sean B. Rourke ^{cd}; Jay Koornstra ^c; Michael Sobota ^f; LaVerne Monette ^g; Steve Byers ^h

^a McMaster University, Hamilton, Canada ^b Fife House, Toronto, Canada ^c Ontario HIV Treatment Network, Toronto, Canada ^d University of Toronto, Toronto, Canada ^e Bruce House, Ottawa, Canada ^f AIDS Thunder Bay, Thunder Bay, Canada ^g Ontario Aboriginal HIV/AIDS Strategy, Toronto, Canada ^h AIDS Niagara, Saint Catharines, Canada

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Between skepticism and empowerment: the experiences of peer research assistants in HIV/AIDS, housing and homelessness community-based research

Saara Greene^{a,b*}, Amrita Ahluwalia^b, James Watson^c, Ruthann Tucker^c, Sean B. Rourke^{c,h}, Jay Koornstra^d, Michael Sobota^e, LaVerne Monette^f and Steve Byers^g

^aMcMaster University, Hamilton, Canada; ^bFife House, Toronto, Canada; ^cOntario HIV Treatment Network, Toronto, Canada; ^dBruce House, Ottawa, Canada; ^eAIDS Thunder Bay, Thunder Bay, Canada; ^fOntario Aboriginal HIV/AIDS Strategy, Toronto, Canada; ^gAIDS Niagara, Saint Catharines, Canada; ^hUniversity of Toronto, Toronto, Canada

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People living with HIV/AIDS (PHAs) in Canada are a highly researched population, yet their inclusion in the research process is minimal. Community-based research (CBR) has become a recognized tool for addressing issues of power and exclusion within researcher/community relationships by inviting the community's equitable involvement as research partners. Within the context of HIV/AIDS research, this includes a commitment to the Greater Involvement of People Living with HIV/AIDS (GIPA) at all stages of the research process. One way of adopting GIPA principles within CBR is through providing employment, research training, and capacity building opportunities for PHAs as peer research assistants (PRAs). Drawing on data from two in-depth focus groups with seven PRAs from the Positive Spaces, Healthy Places: Community-based Research Study, this paper will highlight important methodological practices for academic and community-based researchers who are working with and supporting PRAs.

Keywords: Community based research; Peer Research Assistants; HIV/AIDS; Methodology; Ethics

Introduction

People living with HIV/AIDS (PHAs) in Canada are a highly researched population, yet their inclusion in the research process is minimal. Community-based research (CBR) has become a recognized tool for addressing issues of power and exclusion within researcher/community relationships by inviting the community's equitable involvement as research partners. Within the context of HIV/AIDS research, this includes working within a methodological framework that is committed to the 'Greater Involvement of People Living with HIV/AIDS' (GIPA) at all stages of the research process. One way of adopting GIPA principles within the CBR methodological framework is through providing employment, research training, and capacity building opportunities for PHAs as peer research assistants (PRAs). Drawing on data from two in-depth focus groups with seven PRAs from the Positive Spaces, Healthy Places: Community-based Research Study (PSHP) this paper will highlight important

*Corresponding author. Email: sgreene@fifehouse.org

methodological considerations for working with and supporting PRAs who are involved in doing CBR.

CBR and the Greater Involvement of People Living with HIV/AIDS

CBR is a collaborative partnership approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process (Ahmed, 2004). CBR demands that researchers work in collaboration with the community in order to ensure that research questions address community need and that the results of the research reflect the community's vision of social change in both the social policy and practice arena (Etowa, Bernard, Oyinsan, & Clow, 2007; Israel, Schulz, Parker, & Becker, 1998; Ruetter, Stewart, Williamson, Letourneau, & McFall, 2005). As stated earlier, this necessitates a commitment to GIPA principles which, as stated by the UNAIDS Joint United Nations Programme on HIV/AIDS, is a principle that:

... aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision making processes that affect their lives GIPA also aims to enhance the quality and effectiveness of the AIDS response. (UNAIDS, 2007)

The GIPA principles are reflected in PSHP through a province-wide investigator team that includes PHAs and service providers, and academics who represent various regions and communities throughout Ontario, Canada. Consequently, this has shaped the development of our methodological framework whereby PRAs have been employed to engage in data collection, qualitative data analysis process, and dissemination of findings at both academic conferences and community-based forums.

Background

PSHP is a longitudinal research study that emerged from community concerns highlighting housing as the most unmet need amongst PHAs in Ontario, Canada. In response, community leaders from a range of AIDS service organizations in Ontario led a process of developing a research proposal and applying for funding through the Ontario HIV Treatment Network (OHTN) and the Canadian Institutes for Health Research (CIHR) in order to examine the housing needs and experience of PHAs in Ontario. The successful funding resulted in Positive Spaces, Healthy Places: Community-Based Research Study Exploring HIV, Housing and Health. Six hundred PHAs across Ontario participated in a survey at baseline and at 12 months that asked a range of questions related to housing experiences, access to housing and allied health-related supports, and mental health related quality of life. Fifty of the participants went on to participate in in-depth interviews that focused on housing histories and experiences with housing and allied health-related services. Results are being used to make recommendations for change in housing policy and practice for PHAs in Ontario.

Peer research assistantships

Recruitment

We defined PRAs as people living with HIV who have a history and/or understanding of the impact that housing instability has on the lives of PHAs in Ontario. In

order to reflect the diversity of PHAs in Ontario, we recruited PRAs who also had other identities in common with the study participants such as variations in sexual orientation, gender, and country of origin. We recruited PRAs by advertising on 'Charity Village,' a Canadian community-based and voluntary organization employment website, and through AIDS service organizations and across Ontario. Seven PRAs were hired from the Greater Toronto Area, Central and South West Ontario, Northern Ontario, and Eastern Ontario. The PRAs included: two women, one originally from Guyana and the other from West Africa; one heterosexual white man with a history of drug use; and four gay white men. The recruitment of PRAs adhered to the basic principles of a CBR ensuring equitable involvement of community and building capacity of community members. As such, the PRAs were not required to have any previous research experience since training in research methods was provided. The PRAs have received training at various points throughout the project and have subsequently been involved in recruitment, quantitative and qualitative data collection, qualitative data analysis, and dissemination.

Training and capacity building

The PSHP research team holds the view that community capacity building through employing and training PRAs can and should result in the greater involvement of PHAs in both the policy and practice arenas, and to the development of individual and community empowerment. Nevertheless, several studies have shown that the PRA role raises a number of methodological and ethical considerations (Elliot, Watson, & Harries, 2005). These include: the motivation for employing PRAs that are recognized and trusted members of the community being researched; the use of privileged access to a particular population group; the need to provide on-going support for the interviewers; the difficulties of gaining from the skills and experiences of peer interviewers without exploiting their labor; and the extent to which others are willing to accept their roles as PRAs (Coupland & Maher, 2005; Elliot et al., 2005; Price & Hawkins, 2002). Parallels can also be made between Marino, Simoni, and Silverstein's (2007) analysis of the experiences of peers in providing support to the experiences of PRAs. This is particularly evident in their identification of issues such as social acceptance, reciprocal support, personal growth and empowerment, and resistance as common reasons for peers taking on the research assistant role.

In light of these particular issues, capacity to do the research was supported by providing a range of training modules to the PRAs. The topics included: confidentiality and ethical issues and concerns; verbal and non-verbal communication; diversity of the study participants; administering quantitative surveys; in-depth interviewing skills; qualitative data analysis; and dissemination. The training was facilitated with a combination of lectures by members of the investigator team and guest presenters, role plays, and other experiential learning activities that occurred at various stages of the project.

Methods

The analysis presented in this paper is based on qualitative data emerging from two focus groups with seven PRAs who are working on PSHP. Both focus groups were conducted with all seven PRAs. The first focus group occurred 11 months into the

study which was just prior to their collection of the 12-month data and approximately 3 months later when the 12-month data collection was completed. Both focus groups were between two and three hours long. The purpose of the focus groups were three-fold: (1) to provide the time and space for the PRAs to debrief their experiences with each other, the research coordinator, and the designated investigator; (2) to ensure that our training and capacity building process reflected the needs of the PRAs at different stages throughout the study; and (3) to implement the necessary changes and/or needs that were raised by the PRAs. The focus groups were semi-structured to allow flexibility for the emergence of a range of issues; however, the main themes of inquiry focused on: (1) experience of the training process; (2) reflections about capacity building; (3) issues concerning overall support (educational, emotional); and (4) feedback and suggestions for the development of a PRA training model. This process was incorporated into our overall research funding and ethics applications which were approved prior to the commencement of the study.

The focus groups were conducted by the research coordinator and research investigator who provided the PRA training. This may have had an impact on the degree to which the PRAs felt able to share their reflections and experiences of the training and overall research process. We wondered what impact our long-term and ongoing relationship with the PRAs would have on the outcome of the focus groups given the power that we had as their employer. However, the ongoing and voluntary feedback on training that we received from the PRAs, and their desire to contribute to the development of PRA training more generally, suggests to us that the PRAs brought a high level of honesty and candor to the focus groups sessions. Furthermore, transcriptions of the focus groups were analyzed using thematic analysis and ongoing engagement in reflexive discussions between the researchers and the PRAs. This ensured that the PRAs' experiences were represented in publications and presentations in ways that the PRAs had intended. What follows is a discussion of the findings that emerged from the focus groups with the PRAs from PSHP.

Variations in experience in community-based research

An important issue that arose in the focus groups was related to the range of experience that the PRAs possessed with regard to their understanding of CBR and their involvement in the HIV/AIDS community in Ontario. Although it was not a requirement of the PRAs to have a background in CBR or involvement in the HIV community, at times the training facilitators assumed that the PRAs held a certain level of knowledge that some of the PRAs did not have. As one PRA stated:

In a way, it was all very new to me, I have never been to a conference, I didn't know the lingo, so the process was all very exciting. And it helped that I bonded with everyone who was there ... but I did feel a bit removed ... I felt like the training had already started without me ... but the bonding that took place in such a supportive learning environment, guaranteed, that none of us were left behind.

Hence, at the beginning of the training some of the PRAs felt a bit removed and frustrated because the learning curve was so steep. Their past experiences varied dramatically, so at times it was a challenge for the PRAs to speak from the same page. This suggests two important factors that need to be taken into account when developing research training. First, that the training needs to start from the very beginning; that is, the language of research needs to be understood by all. This includes taking

time at the beginning of the training to go over various terms, definitions, and acronyms related to the research area and tools. Second, providing opportunities for group cohesion including the developing of trust and safety amongst the PRAs will have a significant and positive impact on the training process itself.

Perhaps one of the most important aspects that governed the training was the researchers' increased understanding of CBR and its commitment to involving the community at all stages of the research process. For example, as one PRA stated:

I never had any experience and that was my first experience in doing research in the community and all its aspects Although the training was very intense and there was ups and downs, I am thinking 'I can get this done' you know?

Although the training was intense, the PRAs agreed that it provided them with deep insight into their community and their place within it. They also felt that one of the most valuable lessons they shared as a result of the training experience was the emphasis on CBR and the value that was placed on their involvement within the process. As a result, the PRAs also felt a sense of pride in being involved in the project.

Whose capacity are we building anyway?

Although the training element of the research process became clearer and increasingly accessible over the initial training program, the notion of 'capacity building' remained an interrogated concept. As one PRA recalled:

I remember I was completely skeptical about the whole process Like the capacity building seemed to have come from you guys, but I was unaware that I was being 'capacity built' I felt like the capacity building part was part of the research team's theory; that wasn't explained to the PRA as part of the process. But if I had known that theory, I would have been more consciously, actively aware of it, and maybe have built my capacity further.

The issues highlighted above raise two important points. First, the purpose of employing and training PRAs needed to be made more transparent. There was an assumption on the part of the research training facilitators that the training and capacity building component of the project provided an explanation of what was meant by capacity building. We thought this goal was achieved through providing training on CBR and its underlying principles of social change through community involvement and leadership. However, this assumption resulted in a barrier to honestly discussing and incorporating the PRA's views, needs, and experiences of capacity building. Hence, unbeknown to the facilitators, some of the PRAs initially felt skeptical of the capacity building process and, as one PRA expressed, there existed a weariness of how this would translate into the potential for 'tokenism' of PHAs within the larger research team. The second issue that was raised was linked to the goals of capacity building in and of itself. The PRAs felt that if they had been provided with a clearer understanding of the goals of community capacity building, they would have more consciously worked towards developing their research skills. This is not to negate the fact that the PRAs felt a very strong sense of pride and accomplishment regarding the range of skills they developed and the experience they gained throughout their roles within the study; rather, it is about their desire to have had an increased awareness of this process so that they could have had more control over their individual capacity

building experiences. Having been more cognizant of these issues would have enabled the facilitators to more fully integrate GIPA principles into the training process by providing the PRAs with the opportunity to more clearly identify their personal goals in addition to meeting training needs.

Defining ‘peer research assistant’

The main requirements for the PRA position were people living with HIV who had a strong commitment to working with the broader community in order to create social change, particularly in the area of housing and homelessness. We were aware of the diversity among people living with HIV and as such, were also committed to ensuring that the PRAs that were hired reflected the diversity within the general population. This was not without its challenges, however we remain grateful for the range of experiences and passion represented in our team of PRAs.

One key issue that emerged through the focus groups was the PRAs’ experiences of interviewing other PHAs from communities that were very different from their own and the impact this had on them both personally and professionally. As one PRA explained:

I think as PHAs we are not homogenous you know, we all come from different communities and sort of communities within communities.

This highlights the complexity surrounding the definition of ‘peer research assistant.’ Just what did the PRAs have in common with each other and with the research participants? The PRAs had their HIV status in common with each other and with the research participants, but people living with HIV are by no means a homogeneous community. They carry different histories and identities, and are at different stages of the disease both mentally and physically.

Peer research assistant: insider or outsider?

Differences between PRAs and the study participants raised questions for the PRAs about their status in the HIV/AIDS community. Were they insiders or outsiders within this community? This was not an easy question to answer, particularly for those PRAs who had a longer-term involvement in the HIV/AIDS community as is reflected in the conversation below:

- Researcher:* I wonder if anyone else felt that way, like at times feeling like an insider but also an outsider, as you were doing this work?
- PRA:* Not at all for me because I will always be an insider (laughs).
- Researcher:* Did you always feel like that with every person you interviewed that you were part of their community?
- PRA:* Oh yeah, let me think for a second. There were ones with whom I did not have a history or knowledge of – drug community.

This conversation highlighted yet another important methodological issue regarding the fluid positioning of the PRA’s insider or outsider status in relation to the diverse population within the HIV community.

Insider and outsider status appeared to be influenced by a number of factors such as history of community involvement and experience of one’s self in relation to the

participants. The first example is highlighted through one PRA who came to the project with very little experience of working within the HIV community. When asked about his experience of being a peer interviewer he replied:

I wasn't involved in the community, like many people were involved in the community, so I felt a little bit like an outsider.

Similarly, the PRAs were often administering the survey to people who came to the interview with very different histories and experiences from themselves. At times, this resulted in the PRA feeling more like an 'outsider' than an 'insider.' As one gay white male PRA explained:

If I'm interviewing someone who is an African woman for instance, we have that disability connection but I can't assume to know anything else about her. You feel like an outsider in a way.

Both these examples suggest that the definition of PRA is a far more complex identity than it appears on the surface. This is a particularly important methodological consideration in light of the fact that most researchers or research teams use PRAs in the data-collection process because of the peer's 'insider' knowledge and connection to the community. However, interviewing some participants can make you feel like an outsider if your only connection is through disability and therefore, as one PRA noted, 'we can't assume to know anything else about the participant's lives.'

The PRAs' insider/outsider status was also determined by their perception of their position on the research team. As with other participatory research teams that have employed PRAs, we ultimately benefited from the PRAs' connection to the HIV community (Bonner & Tolhurst, 2002; Elliot et al., 2005; Griffiths, Gossop, Powis, & Strang, 1993). A particularly important contribution that the PRAs made to the team was to the final changes made to the administered survey tool. However, what became particularly clear in our focus group discussion was the PRAs' experience as 'outsiders' among the research investigators. The investigator team was made up of a range of experts in the field of HIV and housing including people living with HIV, and it was this team of experts that were involved in developing the survey tool. However, the PRAs were not invited to our initial survey design meetings. Overall, the PRAs felt that their involvement in the development of the survey tool and as members of the research team more generally, should have begun much sooner. The PRAs felt that they should have been invited to be engaged in the process of developing the data-collection tools as a result of their personal expertise with the types of questions being asked. As one PRA stated: 'How should I explain to you, after all these surveys, like why wasn't a PHA involved in the beginning, instead of the end, you know? Like there should have been PHA involved in the beginning.' This comment suggests that while the team's intention was to reflect the GIPA principles and to ensure that the PRAs were treated and viewed as 'insiders' by the researchers, we failed to do so at this particular point in the research process.

Peer interviewing: challenges and opportunities

The above discussion provides a starting point for addressing both the methodological challenges and personal opportunities that the PRAs encountered throughout the

data-collection process. Prior to the participant recruitment and interview stage of the research, the PRAs were trained on how to conduct an administered survey. This included the ethics surrounding informed consent and confidentiality; ensuring that participants could stop or end the interview at any time without any consequences; the provision of resource and referral information; an appreciation and respect for diversity of experience; and a request that participants arrange for there to be someone they could talk to immediately following the interview in the event that they needed to debrief or seek immediate support. Yet, the PRAs found that even with all the training that was provided to them, they often relied on their own experience and ability to both support the participants through the course of the survey and maintain an appropriate context for conducting research. Hence, at times, the PRAs experienced a high level of confidence because they felt that they were 'talking from the same page' as the participant. However, relying on their experience also 'threw them off guard' and they had to quickly reframe their position with the participant. As one PRA explained:

I drew on my own experience So I had to adjust really quickly. I have no problem saying: 'Ok, now you are talking about something I know nothing about so you are going to have to tell me a bit more about it.' I have no problem telling them they need to educate me.

While this may have meant that the PRAs needed to remind themselves that the person they were interviewing was telling them a very different story from their own, they also took pride in their ability to be 'professional' through supporting the participants in sharing their personal experiences. As such, the interview experience was often talked about as:

... being an honor and an opportunity ... it was a challenge to admit your ignorance, an honor to be witness to the personal stories of struggle, and an opportunity, to grow as a researcher and as a person. The training and ongoing support from the study coordinator and principal investigators helped us to work through the sometimes difficult separation of the personal and professional aspects of this work.

The PRAs entered the interviewer/participant relationship with an initial sense of being an 'insider' to the participant's experience, and then recognized a defining moment when their personal experience was quite different from the participant's. Those moments were taken up as learning opportunities regarding the intersecting issues faced by people living with HIV and how these issues are connected to experiences of homelessness and housing. As such, the PRAs were generally able to find a balance between recognizing the value of their own personal experience and how this could result in valuing the experiences of others. As one PRA stated:

It's empowering to recognize this (the value of personal experience), and it better prepares you to actively listen to the lived experiences of others.

On further reflection, our experience of working with and training PRAs has also revealed an additional layer of learning that requires encouragement and support. There is the actual research training such as ethics, data collection, analysis, and dissemination, and then there is the education and growth that happens more organically through one's process of learning about the diversity within one's own 'community.'

Safety and confidentiality

Another important theme that emerged from the PRA focus groups was issues of safety and confidentiality. As discussed earlier, the ethics protocol surrounding protecting the confidentiality of the research participants was included in the research training. However, what did not become as clear until the focus group discussions was the importance of protecting the safety and confidentiality of the PRAs themselves within the context of the peer interview. As one PRA shared:

Once you built up trust and that confidentiality part, then they trust you, and you feel safe and they feel safe. That's the most important part of working in the community, you have to let people feel it's safe and you have to feel safe. And you know confidentiality and everything is a big, big issue we have to deal with regarding HIV.

Hence, although there was a process in place to ensure everyone's safety and confidentiality, in reality, 'everyone' really meant the safety and confidentiality of the participant. While the PRAs were supported in finding another interviewer in situations that they felt would be uncomfortable or that put them in some kind of conflict, there were no safeguards against protecting their confidentiality. That is, we had no control over what the PRAs shared with the participants and in what the participants shared with others. This issue emerged as quite significant for the PRAs who know all too well the effects of stigma on PHAs.

When the personal becomes professional

Being a peer research assistant is very hard, it's very difficult at some points in time ... but this is my job and I have to be professional.

Working within a CBR framework that is committed to the GIPA principles through training PRAs, can result in the challenge of managing the blurry line between professional responsibility and personal investment. The PRAs were clear about their role; to administer surveys to PHAs about their experiences of health and housing from the time they were diagnosed with HIV to the present time. However, for PRAs working in smaller communities, this meant that they often had some kind of prior and sometimes personal connection to the participants. This resulted in yet another role shift from being in the position of acquaintance, colleague, or friend to a research interviewer. As one PRA recalled:

I was a little leery at the beginning; it's just that I knew the people quite well ... so they were comfortable with me. But in the beginning some of questions, I am going to be asking them some personal questions and all of sudden it's like I am going to hear stuff I haven't heard from them ... I thought I was well prepared until this one person start talking about stuff I wasn't aware of ... and I have to keep it to myself.

Although the consensus among the PRAs was that receiving very personal information from the participants and maintaining confidentiality 'was never an issue' because they were 'used to that,' however, their experiences of being a PRA does raise issues about who can or should be interviewing whom. This brings us back to earlier questions regarding the fluidity of the 'insider/outsider' identity within PRA/participant relations. As mentioned earlier, there were safeguards in place to ensure that both the participants and the PRAs were able to request a different interviewer/

interviewee than the one they were originally assigned (based on region); however, these requests were rarely made suggesting that ensuring that these mechanisms exist may not be enough. This highlights the complexity within the PRA/participant relationship, and the methodological guidelines that need to be developed and followed when engaging in this type of data-collection process.

When the professional becomes personal

Sometimes I feel like I want to change the situation. I want to make their stories of life better, but how can I do that?

The flipside of shifting from having a personal to a professional relationship with participants is when the professional role triggers personal issues and concerns. As such, challenges sometimes arose when the professional became personal. All of the PRAs demonstrated a sense of social and political justice as well as empathy for other people's experiences. These feelings often resulted in a desire to engage in activities that would help to change the participants' lives. Consequently, the separation of personal from professional was spoken about as being quite challenging. As one PRA powerfully stated:

You are talking to people, interviewing them and asking them questions, and hearing their stories ... then it makes me look at myself and say, 'Oh my God' – so that was actually what my experiences was.

Focusing on HIV, day after day, can be overwhelming, especially when PRAs see their own life reflected in another's struggle; the constant personal reflection can be exhausting because sometimes it can feel like 'Your job is affecting all your life.' Recognizing the fluidity of the PRAs' social location is particularly important in discussions about the challenges that the insider role can present for PRAs who have at least one identity in common such as HIV or the worries that are attached to a history of living in unstable housing situations. These include difficulties in separating one's own experiences from the participants', and the significant personal toll that it takes when interviewing people that are experiencing similar issues and concerns. Echoing Haviland, Johnson, Orr, and Lienert (2005), this highlights how being an insider and/or outsider impacts not only how PRAs do research and other kinds of work with their communities, but also upon their personal life experience.

The benefits of peer research assistantships

I guess it's the feeling of being useful again, all of the sudden you feel useful. That's a big benefit, it's a big benefit for health too.

Drawing on the PRA's reflections on their process of training, capacity building, and data collection, it appears that the route to empowerment was as much about being provided with the opportunity to be involved in the research project as the process of doing the work itself:

I was given a chance and there's actually people like (the research trainers) who actually made me feel confident ... gave me the confidence that I need and made me feel

involved in something that I was very proud in being involved to do what I do And after getting involved and actually doing the one-on-one (survey) I felt that I was ready to do it and I was very happy to be given that opportunity.

Hence, although there are some significant challenges that community-based researchers need to address as we move forward in our commitment to community capacity building, the PRAs involved in this study were clearly able to stress the benefits of being a PRA. The personal benefits that emerged from the PRA training clearly reflected the research team's commitment to the GIPA principles. The process of capacity building provided the PRAs with a sense of increased power and control within the research process. This was achieved through the PRAs' increased capacity to provide input on the research questions and data-collection process, and increased confidence in their employability for future CBR studies. As one PRA stated:

I gain(ed) a lot of experience. It used to be hard for me to talk in public, it gave me the idea to go back to school and now I'm able to express myself.

Subsequently, some of the PRAs have returned to school and have moved forward in their lives in 'ways they believe they would never have thought possible.' Others stated that:

The experience changed my life because I felt like I gained some control and power back; moving from the experience of being a PHA as being negative to very positive.

The PRAs believed that the training, capacity building, data-collection process, and overall experience of being employed, resulted in feeling 'useful again' and that their involvement in the research 'benefited their overall health.' However, an important and necessary question regarding the use of their research skills beyond the life of the project was voiced when one PRA aptly queried: 'But when does the PRA position turn into full-time work?' This point elicited a discussion about the sustainability of the peer researching skills, and fears about losing their identity as PRAs and as people who are engaging in paid work that they find personally and politically meaningful. This suggests that in order to fully provide what could be considered to be an empowering capacity building experience for PRAs, considerations regarding support for the sustainability and transferring of their skills and experience should be built into the capacity building process.

Revisiting the journey from skepticism to empowerment

CBR is mainly concerned with the process of developing, investigating, and disseminating research in ways that include the equitable involvement of the community (Israel et al., 1998; Marchand, 2001), and therefore, is not considered a methodology per se. However as illustrated throughout this paper, studies that support a process of community involvement at all stages of the research process, such as the involvement of community members as PRAs, point to the need to address the methodological issues that impact on a PRA's experience within CBR. This echoes Kothari's (2001) argument that while many social scientists engage in a process of reflexivity that acknowledges the influence that their position of power and privilege have on the research methodology and findings, increased attention on the experiences of the

community being studied is also required. What we have attempted to explore here, are how these issues can be addressed within the context of CBR studies that employ and work with PRAs.

Kothari (2001) argues that there is a paradox within participatory research that highlights the ‘desire to fix people’s lives through processes of identification and framing social interaction and activities revealing the rigidity of the methodology’ (p. 148). This assertion urges us to reflect on how the main researchers are implicated in determining the PRAs’ self-perception of their ‘insider/outsider’ status. Hence, the focus-group data shared here highlights the need to call into question the ‘insider/outsider’ binary paradigm not only in relation to PRAs’ positions in the HIV community, but also in relation to the lead researchers. This ultimately demands that in order to successfully implement GIPA principles within the CBR process, we must consciously and consistently ask ourselves how we are using our power to include and exclude PRA participation and knowledge exchange and accumulation. Moreover, we must also acknowledge and address the influence that we have on impacting the experience of PRAs as insiders/outsiders on the research team.

Exploring the PRAs’ experiences of their ongoing role in the Positive Spaces, Healthy Places community-based research study has emphasized the importance of working within a CBR framework that recognizes that the training, capacity building, and support of PRAs does not follow a linear process. Rather, all three elements must be understood as being an intrinsic aspect of the methodological framework and that researchers have a responsibility to ensure that these elements are weaved in and out of the entire research process. This would ultimately result in ensuring that training, capacity building, one-on-one, and group support is provided throughout the duration of the PRAs’ involvement in the project. Moreover, highlighting the ways that their skills and experiences can be utilized beyond the life of the project is equally important when thinking about the sustainable benefits of being a PRA. These factors need to be taken into consideration when developing funding proposals and therefore understood as being an important tool in the provision of an infrastructure for supporting peer research assistantships.

Finally, recognizing the need to continually critically reflect on and assess the PRA model is also exceedingly important as the commitment to the GIPA principles through the involvement of PRAs becomes an increasingly fundamental aspect of CBR. The focus groups with the PRAs have supported this process and consequently, we have increased one-on-one debriefing opportunities and responded to the PRAs’ emerging capacity building needs and interests. Attending to these kinds of issues will enable us to increase our own capacity to engage in the constantly evolving process of inclusion, training, capacity building, and support for the PRAs. This is because, as indicated by the PRAs themselves, addressing these methodological issues will ultimately influence the degree to which they approach their role as skeptics or experience it as empowering.

Notes on contributors

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