

Abstract

Despite the abundance of research on the experiences of researchers with community-based participatory research (CBPR), there has been comparatively little published on CAB members' experiences. The goal of this research was to analyze the lived experiences of a small sample of CAB members in recent health-focused CBPR in Canada, with a particular focus on areas for improvement. We found that CAB members in CBPR experienced low perceived value from researchers due to communication patterns, education differences, and inadequate compensation. These issues may be mitigated through increased CAB member engagement throughout the research process, adequate compensation, and improved emotional support. This study demonstrates that if CBPR methodologies are to live up to their promise, it is crucial that CAB members are enabled to work in true partnership with researchers, receive adequate compensation that is meaningful to them, and are supported throughout the process.

Key Words community advisory board, community-based participatory research

"Very Similar to Having a Pimp": Community Advisory Board Members' Experiences in Health-Related Community-Based Participatory Research

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Introduction

Community advisory boards (CABs) are comprised of a group of citizens who are members of the community of interest and serve in an advisory capacity in community-based participatory research (CBPR); their members may share a common social position, place of residence, or identity, such as ethnicity or disease history.[1-2] Newman et al. [1 p1] described the purpose of a CAB as "an infrastructure for community members to voice concerns and priorities that otherwise might not enter into the researchers' agenda, and advise about suitable research processes that are respectful

of and acceptable to the community". CABs are vital in CBPR, as they increase community engagement in studies through interactions with CAB members [3]; promote ethical conduct as well as the needs and the lived experiences of community members [3]; and play important roles in knowledge translation and application.[4]

Despite the established benefits of community involvement in research, there exists a gap in current literature on CAB members experiences; most of the literature on CBPR is from researchers' perspectives.[5-14] There has been comparatively little published on CAB members' experiences. That which has been published has largely focused on areas for improvement. In light of this limited but important body of work, we were interested in understanding if suggested improvements to CAB member-researcher relationships have been made. As such, in this study we aimed to centre the voices of CAB members and address the questions, "What are the lived experiences of a small sample of CAB members in recent health-focused CBPR in Canada. What areas of their experiences continue to require improvement?" In this paper, we provide an overview

of current literature on CAB members in CBPR, as well as its shortcomings, and detail our methodology, methods, data analysis, and findings from seven semi-structured interviews with CAB members involved in CBPR in Canada.

Literature Review

Numerous researchers have explored the relationships between researchers and CAB members, demonstrating the importance of CABs and providing suggestions to promote healthy CAB member-researcher relationships.[5-14] Nevertheless, academic-community partnerships have often been founded on unequal relations of power.[12] The structure of CABs, while designed to be non-hierarchal, has often been reported to implicitly give more authority to the researchers. [12] Further, many CAB members enter the research process with preconceived beliefs regarding a hierarchy of authority, which affect their confidence levels and relationships with researchers.[12] CAB members have reported feeling that they have limited influence on research decisions, with no authority or legal power, as compared to researchers.[11] Power imbalances also may stem from the unequal scientific knowledge.[13] A multitude of resources are invested in the education of researchers; however, there are often few, if any, mechanisms in place for CAB members to gain scientific knowledge, such as formal health education.[15] This may result in CAB members feeling unprepared or under-valued.[15] Finally, researchers have often perpetuated power imbalances by monopolizing informational and financial resources.[13] The importance of pay has been frequently highlighted when analysing unequal authority, as the lower salaries and the lack of tangible benefits that CAB members receive increase feelings of inferiority.[12]

As a result, researchers have sought ways to ameliorate inequities in power between researchers and CAB members. Wolferman et al. [16] identified the importance of having frequent discussions between researchers and CAB members to evaluate and address CAB members' concerns regarding power imbalances. Chene et al. [6] and Safo et al. [12] identified actively allocating power as a solution to frequently reported dissatisfaction of CAB members regarding power imbalances. Providing continued training on research practices also has been identified as an important solution to increasing the knowledge and confidence of CAB members, further promoting equitable power and authority.[10,14]

Building Trust Through Transparency and Respect

Trust, transparency, and respect are foundational elements in developing healthy relationships between researchers and CAB members.[3,8,17] CAB members have reported researchers giving inadequate attention to building trust. [12] It is crucial that researchers and CAB members devote appropriate time to developing trusting relationships, as CAB members have reported feeling fearful of ulterior motives and of exploitation by researchers.[12] Trust can be established through procedures such as reaching an agreement before making decisions and implementing conflict resolution protocols.[5] Researchers should contribute the effort and the time to engage in team-building activities at each meeting, as well as regularly asking for feedback, which can promote trust in CAB member-researcher relationships.[5,12]

Researchers have also highlighted a significant lack of transparent communication and respect as contributing to feelings of disempowerment among CAB members.[5,12] CAB members in James et al.'s study [7] recalled that researchers resisted sharing information, thus preventing the community partners from being able to make informed suggestions for the research project. CAB members have also reported feeling that researchers have a significant lack of respect for the community members' interests, which left them with an overall distrust in research projects and prevented the formation of sustainable research partnerships.[12] Interestingly, James et al. [7] reported CAB members may also withhold information, consequently limiting the research's scope. CAB members, of course, are sensitive to power inequities, which may result in them circumscribing what they say. Embracing transparency and respect can provide safe environments to cultivate CAB member-researcher collaboration and progress towards shared goals.[5,7]

Researcher-Community Communication

Interactions between CAB members and researchers often suffer due to "outsider-insider tensions".[12 p7] Unintentional misunderstandings and ethnic differences can have significant effects on CAB member-researcher relationships.[12] Tangible research benefits, such as increased insight into the study, have been shown to result from effective communication with CAB members.[6,15]

Effective communication is required amongst members of a research team. [15,18] CAB members can act as liaisons between the research members and the participating community [15,18]; however, for CAB members to be able to connect researchers with communities, they must have sufficient support. [11] CAB members could be better supported through increased communication between meetings, such as email correspondence, and additional in-person communication with researchers. [15] Mwinga and Moodley [9] found lowered literacy levels of some CAB members; therefore, it is critical that

researchers increase information availability by eliminating complex language from their explanations to CAB members.[6] This may also allow CAB members to better communicate with lay community members, educating them about the study and on health promotion behaviours such as HIV testing.[6,15,18]

Ethical partnerships between communities and researchers may be developed if researchers remain openminded and listen to CAB members.[18] In doing so, researchers can develop a critical understanding of the complexity and culture(s) of the populations with which they conduct research.[18,19] Diversity, defined as being composed of differing elements or qualities, must be viewed as a strength to enable the prioritization of culturally safe, inclusive, and equitable research practices,[6,8,19] which are crucial to ensuring the comfort and continued participation of community members.[15]

The above demonstrates that researchers have identified improvements that must be addressed in CBPR to better meet CAB members' needs. Importantly, the majority of these suggestions have been rooted in researchers' experiences and not those of CAB members, and thus these suggestions may fall short of achieving the desired outcome and may, in fact, perpetuate inequities. We questioned whether contemporary practices reflected the numerous suggestions to improve CAB member-researcher relationships that researchers have made and whether the proposed solutions were effective. As a result, we sought to centre CAB members' voices by learning about the experiences of a small sample size of CAB members who have been engaged in health-related CBPR in Canada.

Methodology

For this research, we used a trauma-informed CPBR methodology.[20] While Jumarali et al.'s approach [20] was developed for survivors of assault, trauma-informed care closely aligned with our goals when interacting with participants in our research. Some populations of participants, such as ethnic minorities, may experience vulnerabilities due to their social positionalities and are thus potentially more difficult to engage with through CBPR.[20] Trauma-informed care is a strengthsbased approach to CBPR that centres participants' autonomy and encourages participant-researcher collaboration,[20,21] the goals of which are to promote participants' emotional safety, re-establish participants' control, support participants' coping methods, acknowledge participants' identities and contexts, and develop participants' strengths.[20,22,23] By employing a trauma-informed approach to CBPR, we aimed to respectfully establish engagement in our study with participants who have experienced marginalization.[20,24]

Forms of community engagement, such as empowerment

evaluation, participatory action research, and participatory rapid appraisal, may directly engage with communities for data collection and program evaluation.[25-27] However, we focused on CBPR methodology because researchers who use this approach must centre community members in their relationships, respect the community members by taking a strengths-based approach, and prioritize the unique needs and contexts of community members, even when they do not directly align with the research process.[20,22]

We began by recruiting CAB members for our research. To avoid confusion between the CAB that informed this research and the participants in this research (who had participated in CBPR in Canada as CAB members), we will refer to the CAB for this research as the Overall CAB (OCAB). The inclusion criterion for our OCAB was that the individual had to have prior experience in CBPR as a member of a CAB in Canada. The second author used Twitter to recruit two OCAB members (the third and fourth authors), and she also recruited another OCAB member, a graduate student who met the inclusion criterion. The second author then met with the OCAB members to cocreate and refine interview questions. Research then slowed considerably due to COVID-19, and some changes were made to our research team. The OCAB member who was a student graduated and felt they did not have the time to continue their role in the committee; the other two members remained on the OCAB. We also added another researcher (first author of this manuscript) to the research team to enable the work to be distributed amongst more people, which was necessary due to the impacts of a global pandemic. Both OCAB members from the community were remunerated \$50/hour for their expert insights throughout the entirety of the project.

Methods

Our inclusion criterion for participants in our research was present or past CAB involvement in any form of CBPR in Canada. In doing so, we hoped to obtain a sample with a wide range of experiences. After receiving research ethics approval from the University of Ottawa, we recruited participants via Twitter and Facebook. We also emailed organizations that were known to do community-based work; these organizations shared the research opportunity throughout their networks.

We used semi-structured interviews to collect data. One of the strengths of this interview method, as compared to structured or unstructured interviews, is the balance achieved between free-flowing and directed communication.[28] Although more time-consuming than other research methods like structured interviews, semi-structured interviews permit greater openness and flexibility.[28] Namely, we had the freedom

to add interview prompts in real time, to somewhat direct conversation, while the participants had the space to share meaningful insights.[28] The OCAB members worked with the researchers to co-create the questions.

The second author and the two remaining OCAB members for the overall research conducted the interviews (see Table 1 for participant profiles). The second author led six of seven interviews, with the OCAB members sitting in on interviews when available, asking further questions if desired. One of the OCAB members (the fourth author) led one of the interviews himself. Due to COVID-19 restrictions and a lack of travel budget, all interviews were conducted over Zoom videoconferencing software. The interview questions focused on three main areas: the focus of the CBPR in which the participants had participated; the participants' experiences and opinions of their work as CAB members; and the wavs in which the research reflected the target communities' needs. We closed each interview by asking, "Is there anything I have not asked or anything you have not had the opportunity to say?"; this question was a critical acknowledgement that CAB members are experts on their own lived experiences.

In total, we interviewed seven participants: Four self-identified women and three self-identified men. Despite attempting to recruit participants from a wide variety of areas, all participants were engaged in CABs that focused on health-related issues. The interviews ranged in length from 41 to 102 minutes in length. We paid each participant an honourarium of \$50. We transcribed all interviews verbatim and returned to each participant. The participants had the opportunity to edit them for clarity or to remove sensitive information. Two participants provided minor revisions to spelling of names of people or organizations.

Data Analysis

We used Braun and Clarke's reflexive thematic analysis (RTA) approach [29] to examine interview data from the participants. In 2008, Braun and Clarke [30] first published a paper on thematic analysis (TA). TA is a qualitative analytic method used to identify, analyze, and report themes within project data.[29-31] They later updated their approach to include "reflexive" in the name (i.e., reflexive thematic analysis) to emphasize the researcher's active role in knowledge production.[29] RTA is an adaptable and accessible type of TA, due to the flexibility of choices, such as the inclusion criteria of themes, which must continually be reflected upon by researchers and, if necessary, adjusted.[29,31]

The university through which the research took place has a university-wide licence for NVivo, qualitative data management software; however, it was only available to those who were registered system users, which required the user to be a student, faculty member, or staff member at the university. As a

result, we could not easily find a way to code the data with the members of our OCAB, who lived in different provinces. After discussing this issue, we as a research team decided that the first two authors would do the initial coding of each interview transcript and construct initial themes from the data, and then share them with the OCAB for review and refinement.

RTA requires researchers to reflect on their own positionality. The first author is an early-career scholar who is a white, cisgender, heterosexual, middle-class woman of Ukrainian, English, and Scottish decent. The second author is a senior academic of English and Welsh decent. She is a white, cisgender, heterosexual, upper middle-class woman. The third author is a cisgender, heterosexual, upper middle-class woman of mixed Indigenous and European ancestry who is involved in community-health research. The fourth author is a cisgender heterosexual male of Northern European ancestry who is also engaged in community-health research. By engaging in reflexivity, we became sensitized to how our respective positionality influenced our research encounters, the choices we made in the research processes, and the interpretation of the results.[32] Locating ourselves allowed us to take measures to address the very CAB member-researcher power inequities we were exploring.

Guided by Braun and Clarke's six phases of TA,[30] we first familiarized ourselves with the data by listening to the interview audio recordings and concurrently following the transcripts, which were manually transcribed verbatim. We remained intentional about how our lived experiences affected our interpretation of participants' perspectives on their lived experiences as CAB members in CBPR. We tried to continuously acknowledge the ways in which our positionality influenced the knowledge production process. Next, we generated initial codes in the data by systematically reviewing each transcript with a focus on coding phrases related to our research question. Codes included self-value, community results, perceived value by researchers, unequal communication, tokenism, compensation, education, vulnerability, emotions, marginalization, and improvements.

Braun and Clarke [29,33] advised researchers that while the point of data saturation is impossible to reach, researchers may stop data collection once they have reached an appropriate depth of understanding – termed "theoretical sufficiency." We were cognisant of this throughout our analysis, and it informed our decision to stop collecting data after seven interviews. Phase three of our RTA involved generating the initial themes by sorting codes. We categorized the codes of self-value, community results, and perceived value by researchers under the theme "value." We used codes pertaining to unequal communication, tokenism, compensation, education, vulnerability, emotions, and marginalization to produce the theme "power inequities in the CAB member-

researcher relationship." Finally, we used codes pertaining to "improvement" to include actions CBPR researchers may take to mitigate negative aspects of the CAB members' lived experiences.

Once the first and second author identified quotes that were representative of the main codes and some loose themes, the OCAB members offered their perspective on the data. Upon review, one OCAB member made no changes, and the second OCAB member suggested edits and proposed the recategorization of one quote. This approach tightly aligned with Braun and Clarke's method of RTA.[29] After revising the results section again, we invited the OCAB members to review the findings a second time; one OCAB member had no changes, the other OCAB member provided more insight that greatly informed the discussion section.

Results

Using RTA, we constructed two themes that reflected the experiences that participants had as CAB members in CBPR: a) low perceived value and b) unfair compensation.

Low Perceived Value of CAB Members

Six of the seven CAB members in the study shared the view that CAB members are critical of research and bring significant value to the project. Yet, the CAB members often felt tokenized, undervalued, and excluded by researchers due to communication patterns and education differences. Sabrina, who has been a facilitator for a caregiver support network for almost 30 years, described the value she brings to a research project:

I already come to the table with more expertise than the researcher... If I looked at the data, there is a lot of things that I would see that you [a researcher] wouldn't see. Right? That's the whole reason why you [the researcher] brought me on.

Despite the clear value that the participants felt they brought to the research, most participants revealed feeling tokenized by the researchers. Jenn, an Indigenous woman advocating for Indigenous peoples' participation in HIV research, described how working with non-Indigenous organizations had made her feel: "[The researchers] got to check a box ... Can we consult with one person who self-identifies as Indigenous? Okay, we're good."

While ethnic differences promoted feelings of tokenism in some CAB members, others felt this way due to the researchers' communication, especially a lack of meaningful engagement with them. For example, Matthew, an advocate with lived experience in HIV research, shared, "In some situations, [the

researchers] would want somebody, a community member, because it would look good on paper." Another researcher communication practice that contributed to feelings of tokenism was a lack of researcher acknowledgement of the value that CAB members contribute to the CPBR. Emma, a human trafficking survivor and advocate, expressed that researchers did not recognize the skills she brought to the committee and that she felt, "Infantilize[d] and ... like a tokenized survivor who was just tossed this job because of my lived experience."

Many of the participants discussed how disparities in communication between CAB members and researchers perpetuated a hierarchical structure in the research projects. CAB members were often left out of key decision-making conversations, or, if they were present, communication barriers prevented their input from being taken into consideration. David, a CAB member for HIV research, shared his thoughts about being excluded from decision-making processes: "I thought I was supposed to be a part of those conversations, and I'm not ... You don't get told until a decision gets made and its down the road. And you're like, 'how did that happen?" Even when CAB members were present during research discussions, the language used in the communication often excluded them. Matthew spoke to the importance of researchers using accessible language when he stated that he had been on CABs "where it was heavily academic or heavily involving professional people that the language, the lingo, ... even the acronyms are out of reach of ordinary people." As such, complex language resulted in feelings of exclusion.

Feelings of exclusion were also created by differences in academic achievements between CAB members and researchers. Four of the participants discussed how researchers did not value their lived experiences as highly as academic degrees, which contrasted greatly with the value that the participants placed on their own lived experiences. Participants felt that researchers' lack of value of their lived experiences limited the engagement with CAB members' contributions to the project. For example, Jenn noted that she believed her insights would have been valued by researchers more if she had achieved a higher level of education:

Like, I'm considered an expert in a Zoom meeting, with all these leaders, but then when it comes right down to it... because I don't have a master's or a PhD. ... until I have those letters behind my name ... [I'm] just not going to be [seen] the same way.

The importance that researchers place on academic achievements was also displayed through employment

opportunities. Matthew expressed his frustration when students with more formal academic training than him, but no lived experience, were hired to complete tasks on the research project he was involved with, noting, "I think a greater community involvement is as important as having grad students involved."

Disparities in education between CAB members and researchers not only affected the financial opportunities and occasions to contribute to the project, but they also negatively affected the comfort and confidence of CAB members. For example, Kendra, a CAB member for primary healthcare research, discussed how the differences in education levels have made it difficult for her to advocate for her community:

I still get that nervous feeling if I go to the board, I say something in front of a room, because it is, like, my personal experience, and it's not from a school, and it's not from a type of science and stuff.

Emma, however, argued that power inequities may persist regardless of education level. She spoke about how a researcher treated her, despite her academic and occupational achievements:

She had me do a tracking of my time based on ... 15-minute increments. ... I had to give her a log. ... [A]t that point I had finished my master's, I had like 15 years as a community service provider and started my own non-profit, and I don't at all mind being accountable. But ... it was really belittling.

When asked what steps researchers should take to help CAB members be meaningfully involved in CBPR research, interviewees highlighted the need for strong communication to feel meaningfully included and engaged in the research. For

example, Matthew explained,

People like [anonymized, the principal investigator] ... would ask me questions: "Is there anything you want to say?", "Is there anything that...?" you know? They would come back to me ...just to ... make sure I am still engaged. ...[That] is what I found very valuable, kept me engaged like: "How you are doing [Matthew]?", and things like that kind of stuff.

Participants also argued for the need to ensure that CAB members are part of the entire research process. Sam argued that there was a need to embed patient members of the CAB into every stage of the research:

Involve CAB members from A-Z. So, you're thinking about writing a research proposal? Involve the patients at that point, absolutely. I guess that's where the advisory committee should be starting? ... Right at the very beginning, and at every spot in between, absolutely ...

Actively involving CAB members has significant benefits for the research project and the community. Sabrina noted that research results may be more meaningful to the community if CAB members have equal input as researchers:

If [CAB members] were equal partners, right from the beginning, [researchers] would have ... identified some of those gaps and issues, and those would have just been taken care of. And ... the output would have been more meaningful.

Unfair Compensation

When discussing their experiences as CAB members, participants frequently discussed concerns they had with the

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Table 1: Study participant profiles

Participant (Pseudonym)	Sex (Male/Female/Non- Binary)	Ethnicity	Type of CBPR CAB Experience	Number of Years Involved
1 - David	М	Euro-Canadian	HIV	27
2 - Emma	F	Irish	Human trafficking, social service provision	4
3 - Jenn	F	Indigenous	Indigenous health, HIV	15
4 - Kendra	F	Unknown	Patient partner, Primary Healthcare	5
5 - Matthew	М	Euro-Canadian	HIV/Hepatitis C Virus	3
6 - Sabrina	F	South Asian	Cancer	30
7 - Sam	М	White	HIV/AIDS, Myalgic Encephalomyelitis	10

compensation they received. Many interviewees spoke about researchers' lack of understanding of the emotional work that their role as a CAB member required, and how that was worthy of compensation. For example, Emma described one of her experiences on the CAB as "confusing and painful and jarring." Similarly, Kendra voiced the anxiety she experiences when sharing stories from her past:

For many of us, like because it is anecdotal and the stories like it is what actually happened to us and that can be traumatic or that can be emotional. You know what I mean? Like, it's like so you're either reliving things or you're like telling things that are tied to different emotions... [S]o you're not only contributing like your time, but you're also contributing like your emotions and your stories. And that's a lot on people.

The participants discussed their desire for greater support from researchers due to the emotional vulnerability that comes with sharing their lived experiences with the researchers. For example, Emma contrasted two research projects she had been a part of – only one of which prioritized her wellbeing and was equity-based. She argued,

[Researchers need] a much more ... holistic sense and a recognition that when you're asking people to talk about things that are painful, you need to make sure that their minds and their hearts and their souls and their bodies are just being really wrapped in care.

Six of seven participants connected inadequate compensation to experiencing emotional distress. For example, Emma shared how current compensation practices can leave CAB members feeling exploited:

The ways in which human trafficking survivors are compensated is often done in a way that's really triggering to financial exploitation and memories of being violently and financially exploited...[We're] being asked to engage in these power dynamic financial exchanges that I feel [are] very similar to having a pimp.

Beyond the importance of providing adequate compensation, it is also critical to consider the type of compensation that is being provided to CAB members. Emma spoke about how academic compensation from researchers, rather than financial compensation, contributed to the feeling of tokenism:

If you're not [financially compensated], like, it's tokenizing, right? "Oh, you'll get this in your name if you want as like fifth author. But we didn't pay you." What is that? I mean, it's not like somebody who's struggling

with homelessness ... want[s] to be like a tenure track professor!

The CAB members felt that the researchers valued academic credentials over lived experience; for example, Emma was paid \$5 an hour less than a research assistant with an undergraduate degree, even though she had 15 years of community experience. Sam, who has been on a CAB related to AIDS research, described the need for researchers to place a "dollar value" on CAB members to promote progress in CBPR, stating, "From that paid-for value comes validation, respect, so the researchers and doctors and people in the healthcare field, umm, I think they would view the value of patients, because there's a dollar value attached to them now." Nonetheless, participants felt that they were in precarious positions to advocate for fair compensation. Kendra reflected on conflicting feelings she experienced:

So, it's that pressure of, okay, I shouldn't really do this for free, but I don't want to like say no to people and never be involved again. ... So, I find like always tiptoeing around that stuff ... when it comes to compensation, then, because I don't want to be the person who, like, spoke up too much or, you know, disagreed with their compensation policy or that kind of stuff.

Compensation was clearly a very loaded aspect of CAB members' experiences.

Discussion

By sharing some CAB members' recent lived experiences in health-related CBPR, we promote a more balanced discussion regarding the challenges of CBPR; previous researchers [1,4,14,17] have fallen short of having such discussions because they primarily focused on researchers' perspectives. We also demonstrate that CAB members continue to have struggles with CBPR. The findings from our study present a novel opportunity for researchers and CAB members to learn from the experiences, challenges, and successes of CAB members involved in health-related research in Canada. In this section, we first discuss the findings related to the hierarchy of knowledge, particularly how formal education and lived experiences contributed to tensions between CAB members and researchers regarding expertise. Next, we examine the findings related to CAB members' compensation from researchers and how they related to the broader challenges CAB members encountered in the research projects. Hierarchies of knowledge and inadequate compensation reinforce and legitimize power inequities between CAB members and researchers; in addressing these issues, researchers may better

understand and respond to the needs of the communities they intend to serve.

Hierarchies of Knowledge

The underrepresentation of members of populations that experience marginalization (i.e., LGBTQ2+, persons with disabilities, BIPOC) in academia has been widely documented. [34,35] International efforts to advance the value of CABs in CBPR have gained traction as researchers have illustrated the benefits of community-informed projects and decisions based on lived experiences, which result in stronger research frameworks.[5-14] Notwithstanding such efforts, formal education level remains highly valued in academia, particularly in leading, conducting, and publishing research. Notably, participants in our study identified differences between researchers and CAB members in formal education levels and lived experiences as creating and reinforcing hierarchies. Indeed, four of seven CAB members we interviewed felt that they were less respected and valued by researchers at least in part due to their lower levels of achievement in academia. In fact, education attainment appeared to affect the opportunities CAB members had to contribute to the research.

Our findings show that some participants believed that their lived experience should result in them being at the top of the knowledge hierarchy. Statements such as "I already come to the table with more expertise than the researcher" illustrated how Sabrina viewed her lived experiences as more important than the researchers' formal education. Statements like this were made by CAB members after describing the hierarchies of research that left them feeling devalued. Clearly, there exists significant tension between researchers and CAB members about who is or is not a legitimate "expert." CAB members' calls for a reversal of the current hierarchy in CBRP would nevertheless perpetuate a hierarchical structure. Flattening the hierarchy, so researchers and CAB members have equitable positions in the research, rather than inverting it as some CAB members called for, may be a critical step to addressing both community members' and researchers' needs. Indeed, both forms of expertise are needed in CBPR.

To flatten this hierarchy, bidirectional education of the CAB and researchers must be implemented. Researchers in previous studies largely suggested educating CAB members on the research topic under study.[10,14,15] Suggesting that only one group requires education has harmful implications that further promote the tensions and inequities between CAB members and researchers. Ensuring that CAB members have the opportunity to educate researchers can promote respect and sensitivity for issues faced by the community, as well as provide the opportunity for community-identified respectful practices to be incorporated into the research design. Bidirectional

education may result in power sharing and may minimize the differences in knowledge, allowing the CAB members and researchers to interact with greater understanding and respect.

Adequate CAB Member Compensation: Must Account for Emotional Costs

The findings from our study highlight the need for appropriate compensation for CAB members' time spent on CBPR projects. The CAB members in our research argued that current compensation methods are inadequate; the compensation or lack thereof that CAB members received promoted feelings of inferiority and even caused emotional distress for some participants. Comparatively, when researchers provided adequate financial compensation, CAB members described feeling valued and felt the research project itself benefited from the more equal dynamic that the compensation promoted. Feeling valued plays a particularly crucial role when considering society's negative perceptions of members of groups that experience marginalization who are typically the focus of CBPR.

Researchers have previously elucidated the importance of compensation for CAB members [12]; however, our discussions with CAB members illuminated that the types of compensation they were offered for their work may be due to, and continue to promote, unequal power relations with researchers. Indeed, CAB members are likely to have different values in relation to compensation than researchers. For example, Emma pointed out the importance of considering which forms of compensation might be most relevant to community members when she argued that a person experiencing homelessness does not care about authorship on an academic paper. While this may not be the case for all people experiencing homelessness, she made an important point. Further, power inequities affected the CAB members' comfort in advocating for more appropriate types of compensation.

The way in which compensation is provided is another key area to which researchers must be sensitive. Ensuring financial compensation is distributed to the CAB members by a third party, rather than the researchers themselves, could contribute to diminishing the power dynamic of financial exchanges that Emma identified as being problematic. Indeed, Emma's assertion that she felt much like the lead researcher was acting like her pimp when they paid her highlights the importance of careful management of this aspect of CAB members' research participation.

The findings from our study also illuminated the lack of consideration of emotional work in CAB member engagement and compensation. Previous research has identified challenges that CAB members face, including stigma, low literacy

levels, and lack of support [3,6,11]; however, the emotional toll of research participation on CAB members in particular has received inadequate attention. As evidenced by the fact that three of seven CAB members felt that they experienced emotional distress in their roles on CAB, there exists a need for consideration of the emotional costs of participation on a CAB for CBPR. CAB members may be made emotionally vulnerable during their involvement in research projects. Given the lengthy amount of time that is often required for CBPR research to be completed, this may result in months if not years recounting potentially triggering experiences. Such emotional costs must be acknowledged, minimized, supported, and compensated. Importantly, CAB members expressed fears concerning advocating for adequate and appropriate compensation.

There are numerous ways in which researchers can address the emotional harms experienced by CAB members in CBPR. For example, sources of support that CAB members themselves identify as helpful must be available to CAB members, for free, and without requiring CAB members to first advocate for them. Further, CAB members who need to share and/or work with particularly sensitive information should receive compensation that aligns with the difficulty of such work (i.e., receive higher remuneration). By taking such action in CBPR, researchers can increase the accessibility of research involvement to community members and promote the emotional wellbeing of CAB members as well as respect for their contributions.

Limitations

As with any study, this one has limitations. We identified five limitations with our study. The first pertains to the CAB members only having experience with health-related CBPR. Although interviewing CAB members in health-related research created opportunities to focus on this area, our research may have been even stronger with broader CAB representation from other research fields. Our second limitation relates to the restrictions caused by COVID-19. As a result of them, we were unable to conduct in-person interviews. In-person interviews may have allowed us to develop a deeper, more trusting relationship with the CAB members we interviewed and a more intimate understanding of their lived experiences. [36] Importantly, however, our online interviews enabled us to interview participants from across the country at no cost to the project budget or environment. The third limitation was that we were unable to obtain access to NVivo software for our OCAB members; thus, they were unable to participate in coding the data. After experiencing this issue, the second author advocated for her university to eliminate this barrier.

As a result of her advocacy, moving forward, all community members who are involved in university-related research will be able to access NVivo software free of charge through her university. We hope that this serves as a model for other researchers, even if it came about too late to be of benefit to this research. Our fourth limitation relates to potential self-selection bias in the participants.[37] We recognize that the CAB members we interviewed had largely negative perspectives on CPBR and thus may not be representative of all CAB members' views of CBPR in Canada. Finally, we recognize that there are limits to power-sharing within research processes dominated by Eurocentric knowledge systems.

Conclusion

By listening to a small sample of CAB members recount their lived experiences as CAB members in CBPR, we have promoted a more nuanced understanding of some CAB members' involvement in research and identified new findings, including the need for bi-directional training between researchers and CAB members; the importance of the distribution of payment to CAB members by a third party; and the need to recognize and compensate the emotional work of CAB members. The findings from our study present an opportunity for researchers and CAB members to learn from the experiences, challenges, and successes of seven CAB members involved in health-related CBPR in Canada. By sharing these results with others who engage in CBPR, we hope to play a role in fostering research spaces in which CAB members are respected, included, and valued for their vital contributions.

References

1.Newman SD, Andrews JO, Magwood GS, et al. Community advisory boards in community-based participatory research: a synthesis of best processes. Prevent Chronic Dis. 2011;8(3). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3103575/

2.Strauss RP, Sengupta S, Quinn SC, et al. The role of community advisory boards: Involving communities in the informed consent process. Am J Public Health. 2001;91(12):1938–43. Doi: 10.2105/ajph.91.12.1938

3.Mlambo CK, Vernooij E, Geut R, et al. Experiences from a community advisory board in the implementation of early access to art for all In Eswatini: A qualitative study. BMC Med Ethics. 2019;20(1). Doi: 10.1186/s12910-019-0384-8

4.Yuan NP, Mayer BM, Joshweseoma L, et al. Development of guidelines to improve the effectiveness of community

advisory boards in health research. Prog Community Health Partnersh. 2020;14(2):259–69. Doi: 10.1353/cpr.2020.0026

5.Brock DJ, Estabrooks PA, Hill JL, et al. Building and sustaining community capacity to address childhood obesity. Fam Community Health. 2019;42(1):62–79. Doi: 10.1097/fch.0000000000000212

6.Chene R, Waitzkin H, Thunderchief W, et al. Mental health research in Primary care: Mandates from a community advisory board. Ann Fam Med. 2005;3(1):70–2. Doi: 10.1370/afm.260

7.James S, Arniella G, Bickell NA, et al. Community ACTION boards: an innovative model for effective community-academic research partnerships. Prog Community Health Partnersh. 2011;5(4):399–404. Available from: https://pubmed-ncbi-nlm-nih-gov.proxy.bib.uottawa.ca/22616207/

8.Matthews AK, Castillo A, Anderson E, et al. Ready or not? Observations from a long-standing community engagement advisory board about investigator competencies for community-engaged research. J Clinic Translat Sci. 2018;2(3):129–34. Doi: 10.1017/cts.2018.21

9.Mwinga A, Moodley K. Engaging with community advisory boards (CABs) in Lusaka Zambia: Perspectives from the research team and CAB members. BMC Med Ethics. 2015;16(1). Doi: 10.1186/s12910-015-0031-y

10.Ortega S, McAlvain MS, Briant KJ, et al. Perspectives of community advisory board members in a community-academic partnership. J Health Care Poor Underserved. 2018;29(4):1529–43. Doi: 10.1353/hpu.2018.0110

11.Reddy P, Buchanan D, Sifunda S, et al. The role of community advisory boards in health RESEARCH: Divergent views in the South African experience. SAHARAJ. 2012;7(3):2–8. Doi: 10.1080/17290376.2010.9724963

12.Safo S, Cunningham C, Beckman A, et al. "A place at the table:" a qualitative analysis of community board members' experiences with academic HIV/AIDs research. BMC Med Res Methodol. 2016;16(1). Doi: 10.1186/s12874-016-0181-8

13.Simwinga M, Porter J, Bond V. Who is answerable to Whom? Exploring the complex relationship between researchers, community and Community Advisory Board (CAB) members in two research studies in Zambia. Ethics Politics Community Engagem Glob Health Res. 2020;28(3):65–75. Doi: 10.1201/9781003011187-7

14.Walsh M, Rivers D, Pinzon M. Assessment of the perceived role and function of a community advisory board in a NIH Center of Excellence: Lessons learned. J Health Dispar Res Pract. 2015;8(3):100–7. Available from: https://digitalscholarship.

unlv.edu/jhdrp/vol8/iss3/5

15.Maung Lwin K, Cheah PY, Cheah PK, et al. Motivations and perceptions of community advisory boards in the ethics of medical research: The case of the Thai-Myanmar border. BMC Med Ethics. 2014;15(1). Doi: 10.1186/1472-6939-15-12

16.Wolferman N, Hunter T, Hirsch JS, et al. The advisory board perspective from a campus community-based participatory research project on sexual violence. Prog Community Health Partnersh. 2019;13(1):115–9. Doi: 10.1353/cpr.2019.0014

17. Skewes MC, Gonzalez VM, Gameon JA, et al. Health disparities research with American Indian communities: The importance of trust and transparency. Am J Community Psychol. 2020;66(3-4):302–13. Doi: 10.1002/ajcp.12445

18.Rawl SM, Bailey S, Cork B, et al. Partnering to increase colorectal cancer screening: Perspectives of community advisory board members. West J Nurs Res. 2021;43(10):930–8. Doi: 10.1177/0193945921993174

19.Andajani-Sutjahjo S, Liew TC, Smith JF, et al. Engaging community volunteers in participatory action research in TAMAKI community of Auckland, New Zealand. Health Promot Int. 2016;33(2):219-28. Doi: 10.1093/heapro/daw057

20.Jumarali SN, Nnawulezi N, Royson S, et al. Participatory research engagement of vulnerable populations: Employing survivor-centered, trauma-informed approaches. J Particip Res Methods. 2021;2(2). Doi: 10.35844/001c.24414

21.Ragavan MI, Thomas KA, Fulambarker A, et al. Exploring the needs and lived experiences of racial and ethnic minority domestic violence survivors through community-based participatory research: A systematic review. Trauma Violence Abuse. 2020;21(5):946–63. Doi: 10.1177/1524838018813204

22.Goodman LA, Thomas K, Cattaneo LB, et al. Survivor-defined practice in domestic violence work: Measure development and preliminary evidence of link to empowerment. J Interpers Violence. 2016;31(1):163–85. Doi: 10.1177/0886260514555131

23.Wilson JM, Fauci JE, Goodman LA. Bringing trauma-informed practice to domestic violence programs: A qualitative analysis of current approaches. Am J Orthopsychiatry [Internet]. 2015;85(6):586–99. Doi: 10.1037/ort0000098

24.Vaughn LM, Jacquez F. Participatory research methods – Choice points in the research process. J Particip Res Methods. 2020;1(1):13244–58. Doi: 10.35844/001c.13244

25.Coghlan D, & Brydon-Miller M. Participatory rapid appraisal. In: The SAGE encyclopedia of action research [Internet]. SAGE Pub Ltd; 2014. p. 605-606. doi:10.4135/9781446294406.n267

26.Fetterman D. Empowerment evaluation: A stakeholder involvement approach. Health Promot J Australia [Internet]. 2019;30(2):137–42. Available from: https://onlinelibrary.wiley.com/doi/full/10.1002/hpja.243

27.Baum F, MacDougall C, Smith D. Participatory action research. J Epidemiol Community Health. 2006;60(10):854-857. doi:10.1136/jech.2004.028662

28.Fontana A, Frey JH. The interview: From neutral stance to political involvement. In: Denzin NK, Lincoln YS, editors. The Sage handbook of qualitative research [Internet. Sage Pub Ltd; 2005. p. 695-708. Available from: https://psycnet.apa.org/record/2005-07735-027

29.Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health. 2019;11(4):589–97. Doi: 10.1080/2159676x.2019.1628806

30.Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2008;3(2):77–101. Doi: 10.1191/1478088706qp063oa

31.Braun V, Clarke V. One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qual Res Psychol. 2020;18(3):328–52. Doi: 10.1080/14780887.2020.1769238

32.Darwin Holmes AG. Researcher positionality - a consideration of its influence and place in qualitative research - a new researcher guide. Shanlax Int J Educat. 2020;8(4):1–10. Doi: 10.34293/education.v8i4.3232

33.Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. Qual Res Sport Exerc Health. 2019;13(2):201–16. Doi: 10.1080/2159676x.2019.1704846

34.Martinez LR, Boucaud DW, Casadevall A, et al. Factors contributing to the success of NIH-designated underrepresented minorities in academic and nonacademic research positions. Life Sci Ed. 2018;17(2). Doi: 10.1187/cbe.16-09-0287

35.Syed M, Azmitia M, Cooper CR. Identity and academic success among underrepresented ethnic minorities: An interdisciplinary review and integration. J Soc Issue. 2011;67(3):442-68. Available from: https://bridgingworlds.ucsc.edu/docs-pdfs/Syed,%20Azmitia,%20and%20Cooper%20 2011.pdf

36.Meijer E, Hoogesteyn K, Verigin B, et al. Rapport building: Online vs in-person interviews. Cent Res Evid Secur Threat. 2021. 28 p. Available from: https://crestresearch.ac.uk/resources/rapport-building-online-vs-in-person-interviews/.

37. Compton J, Glass N, Fowler T. Evidence of selection bias and

non-response bias in patient satisfaction surveys. lowa Orthop J. 2019;39(1):195-201. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6604521/

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