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Building Community for Those Living With HIV: Co-Empowerment and Participatory Action Research

Patricia M. Miller Dr.
Mount Royal University, patricia.miller@shaw.ca

Brent Oliver Dr.
Mount Royal University, boliver@mtroyal.ca

Ken LaPointe
Mount Royal University, kenneth.d.lapointe@shaw.ca

Kim A. Samson
Kim Samson, kimba44@live.ca

Vincenzo Sabella Mr.
The Calgary Therapy Institute, calgarytherapyinstitute@shaw.ca

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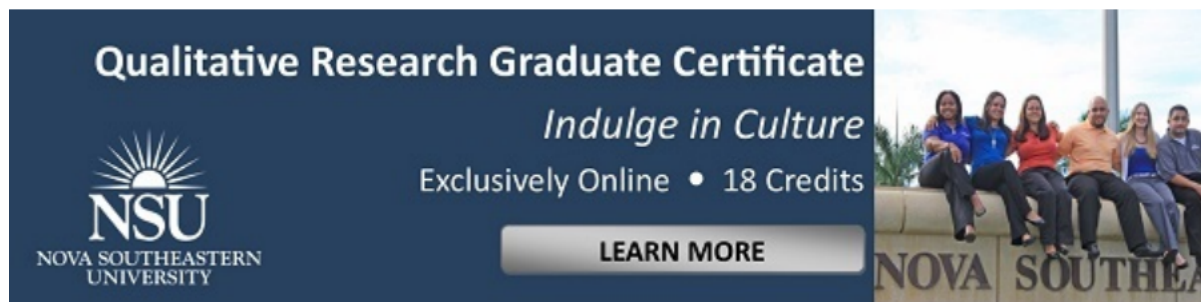


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Abstract

The Calgary HIV Social Society (CHSS) self-determined and organized several social-recreational monthly events to reduce and understand the effects of social isolation and stigma that people living with HIV face every day. It has been found that COVID-19 had impacted the lives of people living with HIV by creating significant isolation for those already stigmatized because of living with HIV. Using a Participatory Action Research (PAR) methodology and focus group at the end of the events, the research showed how COVID 19, and the related concurring isolation has impacted the lives of people living with HIV. The research included three in-person social gatherings with a total of 60 participants living with HIV attending and a focus group with 10 participants. The social gatherings around the city of Calgary, Alberta showed how the possibility of having a safe space and being supported by people who live with similar systematic barriers, buffers the detrimental, social stigmatization of living with HIV and its secrecy. The research brought forth a better understanding on how social connection (including on-line support) during COVID-19 for persons living with HIV increased their general sense of belonging, reduced stigma and was a protective factor for their overall mental health.

Keywords

co-empowerment, self-determination, community, COVID-19, focus groups, HIV, isolation, participatory action research, social gatherings, stigma

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Building Community for Those Living With HIV: Co-Empowerment and Participatory Action Research

Patricia M. Miller¹, Brent Oliver¹, Ken LaPointe¹, Kim A. Samson¹, and
Vincenzo Sabella²

¹Mount Royal University, Calgary, Alberta, Canada

²The Calgary Therapy Institute, Alberta, Canada

The Calgary HIV Social Society (CHSS) self-determined and organized several social-recreational monthly events to reduce and understand the effects of social isolation and stigma that people living with HIV face every day. It has been found that COVID-19 had impacted the lives of people living with HIV by creating significant isolation for those already stigmatized because of living with HIV. Using a Participatory Action Research (PAR) methodology and focus group at the end of the events, the research showed how COVID 19, and the related concurring isolation has impacted the lives of people living with HIV. The research included three in-person social gatherings with a total of 60 participants living with HIV attending and a focus group with 10 participants. The social gatherings around the city of Calgary, Alberta showed how the possibility of having a safe space and being supported by people who live with similar systematic barriers, buffers the detrimental, social stigmatization of living with HIV and its secrecy. The research brought forth a better understanding on how social connection (including on-line support) during COVID-19 for persons living with HIV increased their general sense of belonging, reduced stigma and was a protective factor for their overall mental health.

Keywords: co-empowerment, self-determination, community, COVID-19, focus groups, HIV, isolation, participatory action research, social gatherings, stigma

Introduction

The present study continues the development of a research project started in 2019 (Miller et al., 2021) with the objective of filling the gap between knowledge of the detrimental stigma experienced by people living with HIV (human immunodeficiency virus) and community action. In fact, Oliver et al. (2020) found that among 148 subjects located in Alberta (Canada) living with HIV, the majority avoided community participation because of fear of their status being discovered. The Participatory Action Research project as self-determined by CHSS peer-researchers, and colligatively developed with academic and community-based researchers included three in-person social gatherings which were facilitated during COVID-19, specifically August 2021 a BBQ at Bowness Park, October 2021 at the Fire Escape and Calgary Zoo Lights in December 2021, all events located in Calgary, Alberta.

There were three other events planned which were cancelled, due to the severity of COVID-19 and national lockdowns. Participatory Action Research (PAR) was chosen as a method of inquiry because it generates knowledge for the direct purpose of taking action to promote social change (Freire, 2020; Littman et al., 2021). People with minority status, such

as those living with HIV, constantly experience social marginalization, and this research fulfilled the need of valuing their authentic power, defined as their right to tell and create their story (Miller, 2023). The study as self-determined by CHSS in conjunction with academic researchers was deemed to be an essential actioning of power-with, an in-action research methodology lead by HIV lived experience peer-researchers in collaboration with academic and community research support. Even though three of the six social gatherings had to be cancelled because of “shelter in place” derived from provincial and federal mandates.

The study goals were to continue to reduce social isolation, stigma and seek to reduce the barriers that might inhibit persons living with HIV when facing significant intersectional oppression such as race, class, sexual orientation, and ability, through participatory action-oriented research methodology. The peer-researchers living with HIV saw the need for continued social support as peers-in-the-research and peers-leading-the-research, identified in the PAR project conducted between 2019-2020. The research findings from the initial PAR project found that the benefit for the community members living with HIV, within the social gatherings was that of increased social connection, decreased isolation and stigma while providing academic and financial support for the lived experience peer-researchers.

The use of PAR methodology allowed peer-researchers to create new knowledge while breaking the silence that surrounded the HIV community in Calgary. It offered the possibility for participants to create their story and define their narrative, empowering their perspective and placing the meaning of ‘important’ to what they considered a priority as opposed to what society and the medical system deems as important (Miller, 2018). The later benefit has contributed to the peer-researchers, who are the founders of Calgary HIV Social Society (CHSS) being able to obtain more funding opportunities to continue their organizations mandate to provide barrier-reduced, social-gatherings for the larger HIV community in Calgary, Alberta, Canada.

Knowledge has the Potential to Transforms Bias

Regardless of efforts to educate the public throughout the years, people living with HIV are still impacted by social stigma and discrimination, which undoubtedly impacts their lives (Lo Hog Tian et al., 2021; Miller, 2018; Yuvaraj et al., 2020). HIV targets and weakens the immune system and, if not treated, leads to its most advanced stage: acquired immunodeficiency syndrome (AIDS), the drastic compromise of the immune system that makes the person vulnerable to infections and cancers (McNally, 2019). 37.7 million people across the world live with HIV, 62,790 in Canada (World Health Organization, 2023). Advances in science and medicine transformed HIV into a manageable chronic illness condition. Despite this, stigma, preconceptions, and judgements remain strongly attached to the lived experience of people living with HIV (Mahaboro et al., 2020; Oliver et al., 2020).

The literature has identified some characteristics of living with the impact of stigma in the context of HIV which include: the moral valuations attributed to living with HIV, the ways in which it is transmitted, and population impacted; the intersectionality between HIV and other social determinants of health related to marginalization (socio-economic status, sexual orientation and race); and recognition of societal power relation within mechanisms of stigma (Brown et al., 2022; Mahaboro et al., 2020; Williams et al., 2022). This leads to the overlapping of stigma derived from HIV with homophobia, racism, sexism and other forms of hatred and discrimination shaping the lived experience of people living with HIV (Babel et al., 2021; Miller et al., 2021). Moved by the will to narrow the gap between community and people living with HIV, the Calgary HIV Social Society (CHSS), a not-for-profit organization that operates locally in Calgary (AB), was founded by the lived experience, peer-researchers to provide people with a safe space to be themselves and develop a progressive form of action-

oriented research (Miller et al., 2021). The goal of this study was to provide social gatherings, social understanding, and support, with a commitment to building new knowledge for the larger HIV community and beyond.

Importantly, the context in which this research developed and was carried out was deeply impacted by COVID-19 pandemic. COVID-19 is considered an unprecedented global catastrophe; unlike other global disasters, it spread across the world, unforeseen and unknown, it has delivered a sense of uncertainty and vulnerability (David et al., 2022). The psychological impact of the pandemic has been even more dramatic for people living with HIV, enhancing the lived experience of fear, helplessness, and isolation and a concern about their HIV health and barriers to getting medical care (Chen et al., 2023; Jones et al., 2021). For the CHSS community, the global pandemic added a greater burden to experiences like isolation that people living with HIV already face in acute ways (Miller et al., 2021). The complex web of isolation, deepening socioeconomic vulnerabilities- including loss of social support, increased food insecurity, loss of stable housing, less in-person medical care, concerns about the vaccination and its medical interplay with ART (antiretrovirals) medications, “shelter in place” ordinances and closure of non-medical establishments caused fear, and uncertainty about medical outcomes for those living with HIV (Brown et al., 2022; Nyashanu et al., 2021). The perfect storm of COVID-19 and the social determinants of health, with the lived experience of HIV exposed more vulnerabilities for the HIV community.

Ethical Approval and First Steps

The PAR project ethics approval was obtained from the Mount Royal University Human Research Ethics Board before the COVID-19 pandemic. The ethics approval was a significant experience for the peer researchers as it again validated their voices and that their lived experience would then become a key protective factor in the development of the new knowledge from the in-action research project. No one could have predicted how socially impactful COVID-19 would become in the larger world and what would this mean for the peer-lead research project. Being the research was co-developed with peer-researchers at Mount Royal University, using the innovative method of participatory action research (PAR), the research team used multiple on-line meeting forums to postulate steps forward. There was a sense of urgency as HIV peer-researchers heard from their larger community that people living with HIV were afraid and further isolated. The peer-research team showed significant leadership as COVID-19 provincial protocol was considered once the restrictions were lifted. There was never a moment when the research team thought the research could not happen; it was a matter of how and when to make the action phase of the research happen.

Once the project was formalized the research happened in a socially responsible way, the peer-researchers went to work to figure out the ethically approved public health protocol. This would include the amount of people who could be at the social gatherings, the social distancing required, masking, and hand sanitizer availability as income security was a barrier for some community members being able to attend. Three social gatherings were cancelled due to public health restrictions restricting social gatherings. Finally, in August 2020 the first social gathering (a barbecue) was facilitated with all COVID-19 public health guidelines being followed.

The HIV peer-researchers spent many additional hours formulating plans, talking to medical professionals, and engaging in phone calls or texts with participants to discuss the protocol and get their commitment to follow protocol when attending the events. The research was developed and facilitated by the CHSS peer, academic and community researchers. In this paper, the collaborative research team addresses three main questions: How did COVID impact the lives of people who suffer isolation associated with living with HIV? How creating

community buffers the stigma and social withdrawal of people living with HIV? What are the particular risk and protective factors that moderated the experience of living with HIV during COVID?

Methodology: Action-Empowerment and Knowledge Building

The research method used for this study was participatory action research (PAR), which allows the researcher to gain important insights on complex themes using qualitative research methods, action-oriented processes, a more human methodology that seeks relational connection versus expert-driven knowledge (Creswell, & Creswell, 2018; Miller, 2018; Miller et al., 2021). PAR is particularly suited for research in social psychology, social work, and culturally sensitive domains of care in various people helping professions that not only fosters and promotes local social action but also consents to create new knowledge, innovative and transformative practices (Creswell & Creswell, 2018; Miller, 2018). Within the framework of PAR there is no clear distinction between peer researchers, academic and community-based researchers and participants as every participant is not only considered a source of knowledge, but also an interpreter of that knowledge. With PAR the focus shifts from doing research-on-people to doing research- with-people (Miller, 2023; Miller et al., 2021).

In the framework of participatory action research, reliability refers to the process of inquiry, in such a way that the outcomes are coherent with the experience of the participants and have a solid level of stability across researchers (Lindhult, 2019). The degree of reliability in terms of robustness and consistency of the findings, was assured using a solid research methodology such as PAR that involved peer-researcher participation, reflexivity, and empowerment of the participants (Lindhult, 2019; Miller, 2018). The goal of the research project was to have the HIV community further develop its capacity to create social gatherings to help reduce isolation, while decreasing the impact of stigma and discrimination. The peer-researchers living with HIV, created six social gatherings (three had to be cancelled due to COVID-19) and facilitated three successful social gatherings and one focus group as noted later in this paper. Sixty people living with HIV attended the various social gatherings or focus group. Considering how previous literature is coherent in referring to how people living with HIV experience stigma and isolation (Chambers et al., 2015; Jones et al., 2021; Kalichman & El-Krab, 2022; Marziali et al., 2020; Miller et al., 2021; Rosenfeld et al., 2018) the finding of this research on how community building favors the amelioration of the overall well-being and empowerment of people living with HIV are considered reliable.

The first step in the development of the research was the ethical approval for the research project, which was granted by Mount Royal University Human Research Ethics Board, more details can be found in previous literature (Miller et al., 2021). Considered a milestone in the procedural framework, it has validated the voices of people living with to be heard and seen. Research funding was accessed through an internal grant provided by the Faculty of Health Community, and Education at Mount Royal University. The \$5000.00 grant was graciously accepted by the CHSS peer and academic/community researchers. All funds were used to support the peer-researchers, provide gift cards for food for the research participants, and all other additional funds were used to pay for the location of the events, activity tickets, bus tickets, food, and COVID-19 medical-prevention supplies.

The next phase consisted of the organization of monthly gatherings. The CHSS arranged events and get-togethers for people living with HIV with the objective of increasing the overall psychological and social well-being of the participants. In doing so, the CHSS has followed the international principles of Greater Involvement of People Living with HIV/AIDS (GIPA; UNAIDS, 2007). The social gatherings were well attended by a broad diversity of people living with HIV. In total, 60 people attended and were representative of the HIV

community in Alberta which has disproportionately affected women, gay or bisexual men (Miller et al., 2021). The research participants were recruited through advertisements placed at community organizations, snowball methods through shared connections and from the CHSS community list from previous research. Below in Table 1 is the breakdown of events and numbers of people that attended are listed below.

Table 1

Detailed List of CHSS Events

August 2021- BBQ at Bowness Park	16 participants (maximum allowed)
October 2021- Pottery Painting at the Fire Escape	16 participants
December 2021- Calgary Zoo Lights	18 participants
February 2021- Glenbow Museum	Cancelled due to public health lockdowns
April 2021- Hexagon Board Game Café	Cancelled due to public health lockdowns
June 2021- Movie Night Out	Cancelled due to public health lockdowns
Focus Group – July 24, 2021	7 participants, 3 board members and 1 academic researcher

All the participants were invited to the focus group at the end of the events to gain knowledge and interpret the experience of being able to be oneself, surrounded by people who similarly lived with HIV, and not having to hide. It is worth mentioning, the CHSS gatherings took place throughout the global pandemic, therefore they had to be organized and adjusted according to the Alberta Health Services (AHS), COVID protocols. In this scenario the organizers took on the burden of carrying out best practices assuring the safeness of the meetings and being sensitive to all the barriers, restrictions and compromises that needed to be acknowledged in terms of location, times, and social distancing. The peer researchers engaged the dual role of being lived experience leaders, living with HIV and concurrently, peer-researchers while maintaining participation as a community member. As noted by Miller et al. (2021), the emotional labor of the peer-researchers transpires in how they provide emotional safety and contain the lived experiences of the participants. The generative act of creating new knowledge emerges from the care and assistance of peer-researchers, who selflessly intend to reassign the power to create their narratives to those living with HIV (Miller, 2018). Three gatherings had to be cancelled due to lockdowns. These difficult decisions were made collaboratively by the peers and academic researchers. The cancellation of the three social gatherings required a lot of due deliberation, specific to the ethical considerations for the safety of the participants and researchers.

The Gatherings of the CHSS

March 9th, 2020, when COVID -19 put the world into self-isolation and everyone wearing masks and sanitizing, the CHSS peer researchers were forced to put off the events for the second phase of the participatory action research, until Calgary opened in May 2021. The safety protocols had been implemented to comply with the Alberta Health Care Covid-19 Protocols for the three out of six events remaining. There were screening health questions (which were asked of members, the Thursday, or Friday before the Saturday events), and masks and hand sanitizer used at the events. Lots of participants needed encouragements to attend the events, while others were happy to get out of their homes and see others, they hadn't seen in over a year. The events were held on Saturdays to accommodate members who were working during the week.

In August 2020, a BBQ at Bowness Park (Calgary, AB) was organized, which was accessible by the Calgary Transit Bus/C-Train System. There were fourteen participants

(maximum allowed). Pottery Painting was organized in October 2020, at the Fire Escape (Calgary, AB), there were nine participants and the whole place dedicated to the CHSS members which helped to get participants to come out again, it was accessible from Calgary Transit. One of the organizers escorted three or four participants from the C-Train Station so they could all get on the right bus to the fire escape. The third event was a visit to the Calgary Zoo Lights in December 2020. The Zoo was letting groups in every half an hour to avoid the congestion which entailed separating the participants in different cohorts. The 10 participants were separated into three groups (see Table 1).

The last three events were cancelled as Covid -19 locked everyone down again in January 2021 and they are listed as: Glenbow Museum February 2021, Hexagon Board Game Café April 2021, and Movie Night Out, scheduled for June 2021 (see Table 1). At the three events that were facilitated most of the participants were glad to get out of the house. There were lots of conversations about how they kept themselves busy during the lock down. Some of the activities shared from the participants in their dialogues about their lived experiences were that they read, knitted, and walked their dogs a lot more than before Covid. Some of the members acknowledged that they shut down socially, even with family members, due to Covid-19. A member reported how involvement in social connection had to be drastically reduced “me and a very small group of friends, which we all consider to be high risk [...] decided to keep our close friends close and close the circle.”

CHSS peer-researchers who organized the events had to call people even after they confirmed their participation through emails. The organizers did reminder calls to ask Covid protocol questions, so if members canceled the spot, CHSS could open the spot to the next person on the waiting list. The anxiety regarding coming to these events was articulated by the members to the peer-researchers and it was not only limited to the possibility of contracting COVID, but also to other types of threats. In one instance, a participant reported, “I would have loved to have gone [...] but for me to be coming downtown by myself at night, at my age, is a risk.” Organizers helped to mitigate the fear that the participants felt by acknowledging that it was normal to feel increased anxiety during COVID-19 and engaging social situations. They ensured participant that COVID-19 protocols were being followed and that participants could leave at any time if they felt uncomfortable with the social gathering. None of the gathering caused infections or outbreak of COVID-19, thanks to the scrupulosity of the organizers’ work. The reassurance provided by the organizers and the capacity of all the participants to self-determine their presence and involvement created a comforting and empowering setting that fostered a sense of belonging.

Peer-Researchers: The Roots of the Research Process

All the work done by the peer researchers/participants was not without psychological cost and effort, as identified by the testimony of all people and the transcript of the focus group. All the peer-researchers who organized the events have been invited to co-author this paper and review it. Organizing the events had an impact on the emotional resiliency of the researchers, who had to be available not only to direct the organization but to provide emotional comfort for the members of the community living with HIV. The emotional labor that was experienced by the peer-researchers was compounded by their own experience of living amidst the isolation and burdens that they felt during the pandemic.

Organizers managed to bring together people that would usually hide from the stigma and perception of being judged by the ‘average’ person and society. Creating a comforting, inclusive and non-judgmental setting, they created the basis for conversation to be engaged, reassurance to be shared, and lived experience to be heard. The participants finally had the

possibility to be connected to others who felt similar sentiments, and that could ultimately comprehend what it means to live with HIV.

When using the PAR approach, peer-researchers are the core and spine of the research (Kidd et al., 2018; Wallerstein et al., 2017), involved as co-researchers, they apply action and activism to problems while creating knowledge. The role of the peer-researchers is not only to observe and understand lived experience data, but it is one of being involved in a cycle of defining problems, collecting, and conveying information, determining actions, and studying the outcomes (Miller, 2018). A series of action-oriented steps allow for empowerment and agency for peer researchers as they become stewards for engaging social action on behalf of their community. Though the burden of the multiple roles can lead to emotional fatigue and burn-out. Lastly, the peer-researchers can be conceptualized as the secure base that enriched the CHSS experience, going beyond “simple” emotional support and providing logistic and physical aid.

Data Gathering and Analysis

When adopting a PAR approach, data and information emerge from the participants, their narratives, and their stories (Miller, 2018; Miller et al., 2021). Coherently with this framework, with the aim of doing research with people rather than on people, and with the intent of equally distributing the power between academics and community members (Livingston & Perkins, 2018; Miller, 2018), the events organized by the CHSS allowed for important themes to emerge in the form of meaningful dialogue, which fostered the possibility to identify challenges and problems that people living with HIV commonly face.

Within PAR, every participant wore the hat of the researcher. The peer researchers and organizers of the events were catalysts for the narratives of the participants, in a way that co-empowered them and granted them the occasion to share their lived experience in an insightful way. The lived experiences became information, and the information became knowledge within the action-oriented research. In the spirit of PAR methodology, conversations during the gatherings were not recorded (except for the focus group gathering) inasmuch the aim is to build science-in-action, promote social change, and solve social problems (Miller et al., 2021) and not merely to gather information (Livingston & Perkins, 2018). The open discussion during the focus group allowed participants to create and express further understandings and explanations, as well as attitudes, opinions, and perceptions (Traynor, 2015). The focus group was recorded and transcribed in full disclosure to participants.

The final stage (started in October 2021) of data gathering, and analysis consisted of the extraction of a thematic analysis of the transcript of the focus group. Throughout a series of biweekly online appointments, the peer researchers (Ken LaPointe, Kim Samson) and the academic researchers (Dr. Miller, Dr. Oliver, and Mr. Sabella) developed a collaborative understanding of the social impact and the lived experience of the research participants, through the field experience of the peer researchers which would be merged with the academic researchers. The transcript was color coded and emerging themes were discussed during the biweekly appointments. Disagreements in the interpretation were discussed at length both during the appointments and via emails, always favoring the phenomenological experience of the participants.

Results

From analysis of the focus group transcript and the experience of the participants several themes have emerged to answer RQ1 (how did COVID impact the lives of people living with HIV), RQ2 (how creating community buffers the stigma), and RQ3 (protective and risk

factors). While these factors are identified below in Table 2, it must be kept in mind that the experiences which the events and the focus group refers to happened during the COVID-19 pandemic and has undoubtedly influenced the comprehensive outcomes.

Table 2
Chart of Themes

<p>Impact of COVID</p> <ul style="list-style-type: none"> • Isolation <ul style="list-style-type: none"> ○ Acts of Resistance ○ Building Routines • Emotional Experience 	<p>Importance of Community</p> <ul style="list-style-type: none"> • Social Connections <ul style="list-style-type: none"> ○ Events of CHSS <p>Importance of Being Oneself</p>	<p>Protective and Risk Factors</p> <ul style="list-style-type: none"> • Protective • Risk
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The Impact of COVID

As emerged from the analysis of the transcript with the focus group and from the experience of the events, COVID impacted the lives of people living with HIV in several ways. People living with HIV face a load of negative issues (oftentimes unknown to the general population) which multiplied their challenges during the pandemic, financial uncertainty increased, health concerns (particularly with an auto-immune disorder), social connectedness, and freedom of movement were some of the areas discussed. During the focus group, participants shared experiences of losing jobs, not being allowed to go get groceries, participate in AA meetings, or simply to live normally. Different from the general population, with a not-at-risk immune system, people with HIV lived day-by-day life knowing that any vaccine or cure developed through scientific progress may not apply to vulnerable populations (Singh et al., 2023). Participant’s fear of getting COVID-19 was overcome by the reassurance of the organizers who strictly and methodically followed the Alberta guidelines in preparing the event and ensuring they would be carried out in the healthiest way possible. Humanly, risk can never be totally mitigated, but the awareness of the importance of the research and the connection with the community links provided the courage to run research with the smallest possibilities of risks.

The Role of Isolation and the Emotional Experience

The lived experience of isolation for people living with HIV added considerable weight to the restrictions imposed by the government (curfew, sometimes making the lack of control and decisional capacity unbearable). Some of the participants developed creative ways to gain back part of the control by overcoming and violating the restrictions. Simply going out of the house during the curfew or grocery shopping several times a week. The participants that shared their narratives and these acts of resistance did so to feel some control, within a larger social-medical narrative that they did not feel they had choice in (Todd et al., 2004).

Building routines during the pandemic was a common answer to beat the boredom and the lack of connections that derived from COVID isolations. Reading, cooking, biking, and walking were common ways in which the participants escaped, fought, and resisted the global shut down. The routines helped bring back some normalcy to hours of isolation that blurred hours into days, weeks, and months.

As emerged from the focus group, the fatigue derived from the numerous hours spent online for different reasons (Zoom meetings, gaming, working from home etc.) negatively influenced their mental health. Which did not necessarily entail a negative role of the use of the internet. Mindfulness work and the development of hobbies and habits, such as reading,

and baking increased a sense of resilience which shifted the thoughts from the depressive rumination. A participant reported how the conversation with someone else: “[...] reminded me about reading books and that I reread a lot of my books too, but our library [...] would let you pick up at the door so you could order online and that, that really saved me.” The “survival” language conveys an idea of how distractions constituted pivotal factors in breaching the sense of loneliness and isolation experienced.

A sense of uncertainty, helplessness and hopelessness came from the broadcast of information from the media. A participant reported: “being at home, listening to social media, like watching all the news and stuff they fabricated so much it was really scary to me so I had to distance myself and stop watching the news because it was depressing.” The lack of clear information (i.e., not knowing if the COVID-19 vaccine was safe for people living with HIV) increased the sense of frustration with the present and future situations.

The Importance of Community

The social connections that participants had during the pandemic were a considerable buffer and influence during the experience of the pandemic, as well as the sense of belonging to a community. Interaction with friends and family generated a protective environment that aided in facing the isolation, likewise virtual interaction in on-line chat groups and meetings. Pets were reported as important sources of connection as well, backing the knowledge that simply having a connection sheltered from a sense of hopelessness. Similarly, living with other people was considered a support. A participant reported, “[...] living in an apartment downtown too, with my apartment building there was a good group of super people around, right down from people you just knew on your floor to the staff itself, which really helped.” The simple factor of having people around who shared, cared for, and supported, acted as a life jacket capable of modulating lived experiences.

Participants reported how during such a difficult time, the importance of human connectedness emerged in the experience of strengthening the connections immediately available, like the ones physically close to oneself (i.e., people living in the same building). A participant explained how while cooking and baking were important distractions and hobbies, the sharing of the food cooked in excess was an important occasion to connect with neighbors. A participant reported, “I did a lot of baking as well, but I gave it away to everyone in the building!” These developed narratives showed how linkages and the building of community functioned as an escape from isolation and routine.

As emerged during the focus group, being part of a community such as CHSS substantially improved the overall mental well-being of participants. A participant noted, “I went only to one event [...] and it was really good to get out and just be around people and laugh and joke and just enjoy the day and just feel human again!” The possibility of connecting with people with the same lived experience, beside reducing the “segregation,” has allowed participants to develop connection and participation without the burden of having to keep a “secret.” A participant reported:

[...] definitely the events of the CHSS did help me. It allowed me to feel normal and to be around other people that I knew felt what I felt, without necessarily having to talk about it, and just that sense of normalization helped me not get back in that same closet.

A testimony of the impact of the stigma and prejudice that` was significantly reflected in the language used by the members, who recognize each other as survivors of complex, lived experiences.

The Events of CHSS and the Importance of Being Oneself

People reported fears of aging and being alone, experiences that were buffered by commiserating with other people living with HIV, who fostered a collective resiliency (the capacity of overcoming adverse situations). A participant described how attending the events “helped you feel the weight had been lifted off your shoulders.” The sense of having support and being heard and understood, unknown to people living with, created self-determination that allowed the participants to be powerful agents of their lives, to regain control of their experiences and substantially ameliorate their overall well-being (Miller, 2023).

The sense of belonging and fellowship among the members of the CHSS acted on a different level than other relationships, because there is a shared complex experience which was contained and elaborated, free of judgement, in a protected environment. In one case, a participant disclosed the difficulty that he experienced having to disclose his “living with” to a partner and the negative experience that followed, the group acted as a protected environment that helped frame the experience and provided support and encouragement as the relationship status changed. He referred how:

[...]talking about something, being stressed about something but not telling anyone what it is because, you know, “Something nasty happened and I am really stressed about it,” but you don’t want to disclose the rest of it in the conversation, but amongst this group you can say, “Yeah, I tried to hook up with somebody and told him I was positive and he called me a serial killer, you know?” The fact that I can vent here – that I could vent – with other positive people was important.

One of the last themes that occurred in the discussion was that during the gatherings the participants reported how their stress levels significantly decreased due to the possibility of being themselves. Not having to carry the burden of a secret, where the secret is an act of self-concealment, defined by Slepian (2022) as “an intention to keep some piece of information, known to oneself, unknown from one or more others.” The shared experience of living with HIV and being able to safely identify their status with each other provided a co-empowerment and self-efficacy around talking openly and honestly, without fear of discrimination and stigma.

Risk and Protective Factors

Risk Factors

People living with HIV have a phenomenological perception of reality inevitably filtered by the factor of living with, which particularly emerged during the experiences and events of COVID-19. For instance, the possibility that the vaccine and the cure, in general, was not going to be helpful, or even dangerous, was a fear and a theme that was commonly spread across the participants, which made them, sometimes, doubt the broadcasted news and medical authorities. One of the participants reported:

I do know if they asked if they could get vaccines for people living with [...] and they were told no. I don’t know why, but I do know they asked because they figured we could go there and get our shots, right? They were turned down [...] I have no idea.

The uncertainty in the developments can be seen, as a common experience of the CHSS community.

The rush in finding a solution decreased the attention to these group of people who have a different immune system. Moreover, the experience with the family doctor, for instance, could have been either a protective factor or a risk factor, based on how the practitioner communicated the correct policies and events to the patients living with HIV.

The instability of one's position in the world throughout COVID, job loss and financial uncertainty acted as risk factors as well. Family acted as both a protective and negative factor: it helped provide a constant social connection, yet sometimes this same connection was reported as overwhelming. One participant reported that living with his daughter and son-in-law was a protective factor, but after six or seven months of isolation could be difficult to bear, he reported, "it did affect my mental health and my stability and everything else, and I think it will affect everyone, for a while, quite severely." Whilst the connection with family importantly modulated the effects of isolation, at the same time the deprivation of freedom and changing environment and surrounding people, fostered a sense of imprisonment that could have had a detrimental effect on the participant's psychological well-being. The feeling of being segregated at home and being able only to step outside for a few meters was listed as a risk factor, especially when the subject did not have previously developed hobbies, as a participant said, "my apartment is very small and my balcony is kind of small too, so I was going, like, nutty!"

Physical and environmental barriers, like the location of one's apartment, the distance from CHSS events, the availability of an elevator or the frequency of the transportation and the weather all acted as risk factors. A participant expressed:

In my apartment building, both elevators are broken. [...] So yeah, that was my big barrier having to go down seventeen flights of stair! And when I go home, I have to go back up those seventeen flights of stairs."

And another witnessed how "Transit is a huge barrier to mobility – especially this weekend, apparently!" Financial insecurity undoubtedly was a risk factor that compounded all other risk factors as it would limit the immediate food and shelter resources that people had or could get and impeded travel by bus or cab to and from a grocery store, hospital, or other appropriate destination. The other concern with financial insecurity was that community members could not purchase online resources (if they did not have a computer) and they would not be able to buy things such as a book or other resources to help pass the time.

Isolation

Among the risk factors that negatively impacted the overall well-being of the participants at the events was certainly the sense of isolation and the interruption of the connections with other people, depressive psychological states, and consequent rumination on the negative and detrimental aspects of life. One participant reported, "I just found I became more depressed, continually, and isolated, and even reaching out sometimes, like I live alone, and I find a lot of people that don't live alone don't understand it can be depressing." The sense of isolation did not only refer to the physical barriers imposed by COVID-19, but also to the feeling of having a different experience and lacking people capable of understanding what being alone and living with meant.

Protective factors

A proactive mindset, the will to search for help, social connections, and counseling through HIV Community Links, were protective factors that buffered the effect of isolation and stigma that people living with HIV experienced, leading to a better overall mental health. A participant identified, “I think I only went to one, but it really, really helped, to see people and human beings.” Another participant identified:

I don't have really a lot of friends and a lot of things have changed in my life, it was nice to be around people and just forget about and it does help, I think, with that. Even though we have a common ground we don't talk about it, but it is still a free atmosphere to be who we are, and we don't have to hide that little secret, or whatever. I really appreciated them, so they really helped me out.

Many narratives emerged in the focus about the power of participating in social gatherings and the shared power of being a community in-action as they socially participated.

Cooking, reading, and biking were often referred to as activities that were reported in the focus group. A peer-researcher said:

I probably read two hundred books in the past year and a half and thank God for those little libraries on a stick that is in everybody's neighborhood because I had a box of books I have read, and I picked up a few I could read again – because I had read all my library books.

These coping mechanisms were developed to fill the void of isolation and sometimes had negative downsides. Habits helped maintain an acceptable degree of interaction and were used with this target in mind.

The food that was cooked in excess was shared with the neighbors providing an occasion for a minimum of social contact, similarly, the few fitness activities allowed were a vehicle to get in contact with fitness partners. The routine that was developed was useful in the immediate and short-term time frame. Though discussed were how the negative downsides of cooking in excess resulted in weight gain. A participant pointed out: “I bet I am not the only one – except for two skinny people here – that got bigger during COVID!” The use of jokes and irony is helpful in decreasing negative emotion, building connectiveness and at the same time increase positive emotions and distance oneself from life's adversities (Braniecka et al., 2019). Once again proving how people with living with demonstrate an incredible resiliency in face of adversities and the functional effects of bonding with people who have similar lived experiences. Another participant reported how he had increased shopping online and besides the financial impact, he described the frustration derived from the delay in the shipments and delivery due to the global pandemic restrictions.

Discussion

The focus group on the recreational-social meetings that the CHSS hosted was the useful tool to gain access to the information on how the events ameliorated the overall psychological well-being of people living with HIV. The connections created among the participants helped buffer many of the negative effects of isolation, loneliness, stigma, and prejudice experienced in daily life by people living with HIV. “[It] was something that kept me busy, kept me seeing somebody else, anyway, and I guess kept my mind off my own problems,”

witnessed a participant. The positive connections broke through the burden of COVID-19 fears, isolation and chronic loneliness and increased the general emotional well-being of the participants of the gatherings.

New knowledge was generated from the same people who held that knowledge and finally had a chance to share the lived experience and the meaning of it. The CHSS empowered people living with HIV providing the space for their voices to be heard. Stigma, stereotypes, and isolation were faced with connectedness, selflessness, and accepting stances. The gatherings created a welcoming atmosphere where participants had the opportunity to self-determine how their experience was narrated, therefore regaining the right to tell their story to someone that was open to listen and understand it.

The present study confirms the psychological burden that people living with HIV experienced during COVID 19 pandemic (Kalichman & El-Krab, 2022; Pantelic et al., 2023). Coherently with previous findings, it showed how the experience of COVID-19 together with the burden of living with HIV, impacted people in a different way, adding to the phenomenon of isolation and stigma. Differently from what was shown by Kalichman and El-Krab (2022), an increase in the abuse of alcohol and substances did not emerge or was not reported by the participants.

The study adds to previous findings on how building community and providing a safe space helps improve the overall well-being of people living with HIV. People living with HIV are stigmatized and live in a state of social isolation in a proportion remarkably greater than the “normal” population (Marziali et al., 2021; Marziali et al., 2020; Oliver et al., 2020). Rosenfield et al. (2018) found that one of the two main strategies that people living with HIV use to buffer the stigma and social isolation is via establishing social contacts or support from external agencies. It is therefore detrimental when living with HIV, is met with a lack of either of those, particularly because of the restrictions imposed to limit the spread of COVID-19, during the pandemic.

Coherently with Rosenfield et al. (2018), as was found out during the events of the CHSS and the focus group, people living with HIV frequently build a network of services for different needs that assume the role of reference points (i.e., the library, social organizations, support groups and medical services) which act as protective factors, and these resources were interrupted or sensibly impaired, resulting in negative impacts on everyday life.

All the participants created a sustaining network and built a community of mutual help. As it emerged from the findings, the dialogue between the members built a sense of camaraderie and trust that buffered the everyday stigma, prejudice, and negative experiences, including COVID, that the participants faced. The members of the CHSS have developed connections and fostered social action to be heard and understood as a community. The group moderated and reduced the shame that oftentimes comes from having a need (Ryökkönen 2022; Yakeley, 2018), normalizing the lived experience of having a problem, and promoting solutions and support. People living with HIV often feel dehumanized for their situation, where feeling human embeds the sense of human “uniqueness” and “nature” (An et al., 2022; Miller, 2018), therefore they are attributed an implicit status of less valuable, incapable, unworthy, and inferior. Throughout the focus group, it emerged how meeting with other members fights this detrimental experience reattributing the worth of a person and the right to be heard by the participants.

Furthermore, the language that the participants decided to use, terms like “resurfacing,” “being alive,” “reignites,” and “safeness,” carries the importance and depth of the feeling experienced. The emotional load is reflected in the language (Braun et al., 2019; Tackman et al., 2019) of these words providing the full sense of the burden of the isolation, stigmatization and exclusion lived and how the gatherings were their deep breath in an uncertain drowning world. The use of self-determined language would be endorsed by response-based theory which

would honor the resistance and the reclaiming of their personal power through their actions and language (Miller, 2023; Todd et al., 2004). Self-determined language as found in the focus group, lived experience data allows persons living with HIV to reclaim their lived experience, with empowerment through the narratives they provided.

The organization of the CHSS social recreational events through the efforts of the peer-researchers helped moderate the stressful experiences of stigma and isolation lived by people living with HIV. The peer-researchers protected the participants' mental health and wellbeing fostering an environment that promoted inclusivity, social interaction, the possibility of being understood, a sense of belonging and the freedom of being oneself. All phone calls, emails and in-person events were significant emotional anchors to those who live with HIV.

The social connections built by the peer researchers favored an environment of mutual support in which the participants of the gatherings helped each other even at the cost of not participating in an event. During the focus group, one of the members reported how, due to an emergency, he decided to "rescue" a fellow participant in a moment of difficulty, so giving up the possibility of participating in one of the social activities. Knowing that he would be valued in making that decision created a deep sense of connection and validation in his choice. It was reported, "my friend with the addiction problem, each and every time one of the events came on, he ended up having an anxiety attack! For the Zoolights I took him to the hospital [...]."

Lastly, the connections that were created during the CHSS social-recreational gatherings promoted a climate of mutual help from an organizational point of view as well. Each member took the role of promoter and defender of the group, which looked and proposed solutions to help the continuity of the CHSS meetings facing the issue of lack of funding. The positive, creative, and proactive communication among the participants was a protective factor that aided the search for the best logistic and organizational solution on each level, from the share of information to the future perspective. Throughout the focus group it has emerged the vastity of the detrimental emotional experiences that people who live with HIV must face in everyday life and how the CHSS social recreational events help to cope and moderate that.

Limits

A limit of the study is the absence of follow-up after the events for CHSS have ended because of limited financial resources. Another possible obstacle is the absence of a comparing group with which contrast the results of this research by allowing there to be a group of persons living with HIV identifying barriers and experiences for the lack of social support. There are limitations on the people living with HIV that were included in this study. Those included were known to the community and referred by other members which already had established itself in the original research project. The peer-researchers diligently sought out ways to connect with those less known to the HIV community. Those more marginalized and are less known and less visible might benefit from being a part of the social outings and social-action research. Lastly, there was a smaller number of younger adults, and an overall lack of diversity among the participants. The research would have benefitted from people with a different background, a different lived experience, whose voice is important in understanding the need for future supports and succession planning for CHSS and future shaping, social-action research projects.

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Author Note

Dr. Patricia Miller is a contract instructor in the Department of Child Studies and Social Work at Mount Royal University and a community-based researcher. She is dually registered as a clinical Social Worker and Clinical Psychologist. She has completed two doctorate degrees: one in behavioral and social science and the other in clinical psychology. Dr. Patricia Miller is a collaborative academic researcher that worked with CHSS peer researchers on this participatory action research project. Please direct correspondence to patricia.miller@shaw.ca

Dr. Brent Oliver is an Associate Professor in the Department of Child Studies and Social Work at Mount Royal University and a community-based researcher. He has worked with community and academic collaborators in Calgary on a wide variety of research projects focused on HIV and Stigma, HIV supportive housing and clinician training. Please direct correspondence to boliver@mtroyal.ca

Ken LaPointe HIV Lived Experience Positionality Statement Ken is a peer researcher and president of CHSS. He was diagnosed 32 years ago in 1988, the same year as the Calgary Winter Olympics! He became seropositive likely between 1984-1986 during a time of great fear and ignorance. Without medication to combat HIV directly, it was a time of great peril. He was one of the few survivors of the 1980's to see the advent of the first medications released in 1989, AZT. Later, drug cocktails normalized the disease to a non-life, threatening condition. Medical advances were far faster than the harmful social conditions of stigma that still largely remain today. He became President of the Society after its incorporation in 2019 to find a grass roots approach to provide much needed social service and fellowship for marginalized people living with HIV in Calgary. It has been our theme to create, in a sense, a "new family" of choice. He is current president of CHSS and in his organizational capacity, he has hosted AGM's, board meetings, assisted with society banking set-up, the first focus group moderator, created society logo and graphics and fully participated in all social gatherings. Please direct correspondence to kenneth.d.lapointe@shaw.ca

Kim Samson HIV Lived Experience Positionality Statement Kim is a peer researcher and the secretary for CHSS. After diagnosis March 2011, Kim immediately started volunteering throughout the HIV Community, giving back by cooking Friday lunches, stuffing condom packs, and attending events through HIV Community Link. Kim volunteered with the Alberta HIV, HCV and STBBI Advisory Consortium as a population specific person from 2015 until 2018. Kim is currently volunteering with the Positive Voices Caucus (ACCH) since 2016. Kim is also on the Peer Advisory Committee for HIV Community Link Peer Programs since 2017. Kim is a well-rounded public speaker and has spoken to many topics related to HIV, including Normalizing Testing for early detection, the importance of antiretroviral compliance, the U=U movement, Women and HIV, and the impacts of stigma and isolation on people living with HIV. Kim remains an active volunteer in the community where she is currently Secretary/Treasurer for the Peer started Calgary HIV Social Society (CHSS). Kim is also a Peer Researcher with the REACH Community Based Research Alberta Stigma Index Project. Kim is an advocate and activist who is passionate about helping people living with HIV get the support they need, as well as educating the public about the myths of HIV. She firmly believes that we are stronger together and that remains a driving force in her tireless efforts to give back to the HIV community. Kim is a board member of the CHSS society, who holds various positions and acts as a co-treasurer for the organization. Kim was heavily involved in the pre and post development of the social gatherings as well as the focus groups. Kim was responsible for the society registration process and general keeper of CHSS records, activities and served as a liaison with funding providers. Please direct correspondence to kimba44@live.ca

Vincenzo Sabella is the research coordinator at the Calgary Therapy Institute and is involved in community-based research projects. Please direct correspondence to calgarytherapyinstitute@shaw.ca

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