
9-7-2021

High Touch Research: Building Community for Those Living with HIV

patricia m. miller Dr.
Mount Royal University, patricia.miller@shaw.ca

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

Kenneth Lapointe
Mount Royal University, kenneth.d.lapointe@shaw.ca

Kim Samson
Mount Royal University, kimba44@live.ca

Kate Berezowski
Mount Royal University, kbere364@mtroyal.ca

See next page for additional authors

Follow this and additional works at: <https://nsuworks.nova.edu/tqr>

 Part of the [Quantitative, Qualitative, Comparative, and Historical Methodologies Commons](#), and the [Social Statistics Commons](#)

Recommended APA Citation

miller, p. m., Oliver, B., Lapointe, K., Samson, K., Berezowski, K., Nelson, K., & anonymous, K. (2021). High Touch Research: Building Community for Those Living with HIV. *The Qualitative Report*, 26(9), 2837-2850. <https://doi.org/10.46743/2160-3715/2021.4857>

This Article is brought to you for free and open access by the The Qualitative Report at NSUWorks. It has been accepted for inclusion in The Qualitative Report by an authorized administrator of NSUWorks. For more information, please contact nsuworks@nova.edu.



High Touch Research: Building Community for Those Living with HIV

Abstract

Participatory action research can be a research methodology that seeks to offer relational processes that develop high touch research relationships, create co-empowerment, while fostering resiliency and strength, within the HIV community. The Calgary HIV Social Society (CHSS) in Calgary, Alberta, Canada co-developed with peer-researchers at Mount Royal University, a progressive form of action-oriented research that allowed the HIV community to develop and provide social gatherings to reduce the impact of stigma and isolation. The research project was developed with the community of people living with HIV to reduce the impact of isolation and stigma. The focus of the research was to better understand how social gatherings could improve the quality of life for those living with HIV. The action-oriented methodology allowed for HIV peer-researchers to bring their expertise on what was needed to reduce stigma and isolation. The HIV social support community created participatory action research processes that successfully contributed to building an inclusive, community for people living with HIV. This paper will share the themes that acknowledge the significant impact that a HIV high touch relationship research community can have for those, who face the barriers of isolation and stigma by increasing community connection, reducing financial constraints that limit participation, while increasing mental health wellness.

Keywords

participatory action research, social gatherings, co-empowerment, HIV, stigma, isolation, high touch research relationships

Creative Commons License



This work is licensed under a [Creative Commons Attribution-NonCommercial-Share Alike 4.0 International License](https://creativecommons.org/licenses/by-nc-sa/4.0/).

Acknowledgements

We would like to thank all of the people that participated in the social gatherings. Their participation helped us to understand the importance of providing a safe, accepting and barrier free space to gather and explore the meaning of living beyond HIV-focused stigma, while reducing isolation.

Authors

patricia m. miller Dr., Brent Oliver Dr., Kenneth Lapointe, Kim Samson, Kate Berezowski, Kirsten Nelson, and Kevin anonymous

High Touch Research: Building Community for Those Living with HIV

Patricia M. Miller, Brent Oliver, Kenneth Lapointe, Kim Samson, and
Kate Berezowski
Mount Royal University, Calgary, Alberta, Canada

Kirsten Nelson
University of Calgary, Alberta, Canada

Kevin anonymous
Mount Royal University, Calgary, Alberta, Canada

Participatory action research can be a research methodology that seeks to offer relational processes that develop high touch research relationships, create co-empowerment, while fostering resiliency and strength, within the HIV community. The Calgary HIV Social Society (CHSS) in Calgary, Alberta, Canada co-developed with peer-researchers at Mount Royal University, a progressive form of action-oriented research that allowed the HIV community to develop and provide social gatherings to reduce the impact of stigma and isolation. The research project was developed with the community of people living with HIV to reduce the impact of isolation and stigma. The focus of the research was to better understand how social gatherings could improve the quality of life for those living with HIV. The action-oriented methodology allowed for HIV peer-researchers to bring their expertise on what was needed to reduce stigma and isolation. The HIV social support community created participatory action research processes that successfully contributed to building an inclusive, community for people living with HIV. This paper will share the themes that acknowledge the significant impact that a HIV high touch relationship research community can have for those, who face the barriers of isolation and stigma by increasing community connection, reducing financial constraints that limit participation, while increasing mental health wellness.

Keywords: participatory action research, social gatherings, co-empowerment, HIV, stigma, isolation, high touch research relationships

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.” -Margret Mead

HIV is a chronic illness that people live with across their lifespan. Stigma, mental health, and social isolation are prevalent among a variety of psychosocial issues experienced by people living with HIV in Canada. Despite significant treatment progress, stigma continues to impact the quality of life and health outcomes of people living with HIV worldwide (UNAIDS, 2017). This is also the case locally; in a recent survey conducted with 148 diverse adults living with HIV, a majority reported recent experiences of stigma and hiding or isolating from their communities out of fear of these negative experiences (Oliver et al., 2020). HIV stigma frequently intersects with homophobia, racism, sexism and other forms of

discrimination in shaping the lived experience of people living with HIV in Canada. There was a gap between lived experience, knowledge translation and community action from the medical/academic community and the larger HIV community. This gap was understood and discussed by our team of researchers to ensure that we were providing those living with HIV safe and respectful social connections that were identified by the participants themselves versus what the academic researchers thought they needed. The importance of our research highlights the collective focus on the needs and wants of those who face the stigma and isolation when living with HIV.

Subsequently, a majority of people living with HIV experience mental health issues with depression being especially common (Choi et al., 2016). Social isolation is also pervasive and is closely associated with unstable housing, experiences of violence, and diagnosis with a mental health condition (Marziali et al., 2020). A recent study in Canada found that these issues intersect with poverty, trauma, and stress in having a detrimental effect on the health of people living with HIV (Gibson et al., 2011). Trauma in particular is seen as a syndemic factor in HIV infection contributing to substance abuse, poor health outcomes, and a low adherence to medication among people living with HIV (Brezing et al., 2015). Many people living with HIV seek support for these issues, however care is not available for all and those who identify as gay, as having low income, or as immigrants to Canada are less likely to access the support and care they need (Choi et al., 2016).

Despite these challenges, people living with HIV have been at the forefront of the development of HIV/AIDS service programs. Early demands for self-determination led to the establishment of the Greater Involvement of People Living with HIV/AIDS (GIPA) principles. Adopted internationally, the GIPA principles recognize the rights and responsibilities of people living with HIV including the right to self-determination and participation in decision-making processes that affect their lives (UNAIDS, 1994). Even with these universal principles many people living with HIV had little involvement or input in the planning and development of local HIV care and support programs and there has been a call for more peer involvement in the development of HIV service programming (Collins et al., 2007; Canadian AIDS Treatment Information Exchange, 2018).

A More Human Methodology

The CHSS research project began with a shared understanding that HIV lived experiences and the GIPA principles are foundational to empowering inquiry. Building upon established social-relational networks, a peer-led, participatory action research project was conducted to explore the benefits and challenges related to peer-led social gatherings for people living with HIV in Calgary, Alberta. At the heart of this action research was a respect for the knowledge of the lived experience within the HIV community and aspirations to engage in meaningful collaboration, contribute to the well-being of all participants, and support capacity building within the HIV community itself. Participatory Action Research (PAR) is a method of inquiry that generates knowledge for the direct purpose of taking action to promote social change (Freire, 2000). The CHSS research project was a critical inquiry project that began with the community itself taking action to develop their own not-for-profit status and inviting in academic researchers to help them explore the benefits of social gatherings.

This invitation from the HIV community to create social gatherings and develop a research process with MRU researchers about the practice of community development through praxis (merging research and practice) and collaborative processes including building trust, creating community action, and developing new knowledge (Kimjin Traver, 2004) allowed for the HIV peer researchers to better understand how to develop action-oriented research practices that would contribute to community building. According to Bradbury (2015), there are two

objectives of PAR: to produce knowledge and action directly useful to a group of people, and to empower people at a deeper level by developing the process of co-researching and co-construction to build capacity in the community. This participatory action project was closely aligned with the principles of PAR in that it sought to empower participants and build on the social capital that already existed within the HIV community and develop lived experience understandings through critical inquiry with community members. The PAR approach encompassed a rigorous step-by-step framework in order to build trusting relationships with the community and develop sound academic processes in order to create new knowledge for the community from all of the substantial inquiry and action taken.

This shared approach was characterized by the values of participatory inquiry including a focus on respectful dialogue, relational learning, ethics, and power sharing strategies (Wallerstein et al., 2017). Subsequently planning, analysis, review, and meaning making of the data was undertaken jointly by lived experience community members and researchers. The participants living with HIV, who engaged the social gatherings were identified by the peer researchers through a snowball sampling process. The community members were adults living with HIV and included the intersectionality of diverse gender identity, social location, race, ability and duration of living with HIV. Many community members were facing financial barriers, racial discrimination, trans and homophobia as well as living with a differing health ability and had experience health inequity because of the intersectionality of social location and living with HIV (Kaufman, 2005).

The benefits of participatory inquiry to participants and community members include increased collaboration, integration of HIV community-led knowledge, development of action-oriented processes that decrease social barriers, and leadership that can support HIV community-led social-support models of care (Flicker et al., 2008). The co-researchers were formal leaders in their social gathering community and were the people who contacted the participants and facilitated the social gatherings, while being supported by their partners that were academic community-based researchers. The process of developing the steps for the PAR methodology was done at two different meetings on the MRU campus and through various phone and email communications that included a clearly delineated series of steps and responsibilities. These co-navigated steps were foundational to the requirements of a PAR methodology that seeks to develop shared power relationships that co-empower the community that it collaboratively seeks to work with (Baum et al., 2006).

Steps taken were identified as: who would write the funding and ethics proposals, how would the social gatherings be structured, how and who would contact the community members, how would the lived experience data be gathered and who would review the data and disseminate it? The steps were reviewed at follow-up meetings that eventually had to be moved on-line due to COVID-19. Within this process of inquiry, PAR bridges relational practices and rigorous science-in-action approaches (Fals-Borda & Rahman, 1991). The action points were thoroughly discussed, deadlines adjusted based on the needs of the lived experience peer researchers, while timelines were still met under the pressure of combining academic expectations and lived experience emotional burdens. The high volume, low touch approach of scientific academic research was replaced with a high relationship development and lower academic pressure out-put that ensured the HIV community peer-researchers were ready and safe in the research process.

Methods: Social Gatherings and Focus Groups

This project of inquiry was a collaborative partnership between academic researchers and the Calgary HIV Social Society, which is a community of committed persons that live with HIV. The Calgary HIV Social Society was developed through a series of conversations that

began with HIV peers talking about the need for there to be a social format that would allow persons living with HIV to come together. Some of the peer researchers that were living with HIV had been peer facilitators in another peer-support program that originated from Dr. Miller's original PhD. research on the benefit of peer-support for sero-discordant couples living with HIV in Calgary, Alberta. The peer-support group was fully viable in the HIV community as it was now funded and managed through HIV Community Link. The original group of peer researchers living with HIV contacted Dr. Miller to discuss their ideas about wanting to develop a peer-driven, social format, peer-facilitated gathering process for the HIV community. The HIV community sought direction from Dr. Miller on how to start the process of developing the research and funding options. Through many more conversations a decision was made by the community to develop their own not-for-profit agency that would allow them to self-regulate their process which they then called the Calgary HIV Social Society. They envisioned their social gatherings to be less formal, while challenging barriers such as lack of finances for participants to come to social activities in order to reduce isolation and the paperwork that caused the other community peer-support program to be less accessible and desirable for persons living with HIV.

Dr. Miller contacted Dr. Oliver about funding options at MRU and all members of the collaborative research team met in the spring of 2019 to develop a formal plan of action. The participatory action research methodology allowed for the community members that live with HIV to be co-participants in the research and while contributing to the overall development of capacity within their community. Once the research team was established it met to develop reciprocal relationships, discuss project methodology, and build a rigorous process in order to implement the research. Ethics approval was obtained from the Mount Royal University Human Research Ethics Board. The ethics approval was a significant experience for the peer-researchers as it validated their voices and that their lived experience would then become the narrative medication that could support others in the community to live well with HIV.

Ten monthly social gatherings for people living with HIV were organized by the co-researchers from the CHSS. The social gatherings were designed to encourage peer support, reduce stigma, increase relational understanding, and identify strategies to reduce isolation. These monthly meetings consisted of 2-hour gatherings that involved social-recreational activities facilitated by the co-researchers from CHSS. Each month a different activity and location was decided upon with input from participants. There was no cost to attend the social gatherings for participants. Travel expenses and refreshments were provided by the CHSS at each gathering. Each participant was given a Walmart gift card that was valued at \$20.00 for their participation. The social gatherings were well attended by a broad diversity of people living with HIV. In total, 64 people attended and were representative of the HIV community in Alberta which has disproportionately affected women and gay or bisexual men (Siemienuk et al., 2013). The majority of the participants were male-identified persons and co-identified as being gay or transsexual. Their observed age would be in the 40 years plus. This intimate personal information was not required of the participants in order to reduce the impact of the medical economic world in which personal data is always taken before people can be helped. Many of the participants were facing financial barriers as they described not having to pay for the social gatherings as a significant benefit to their current financial situation.

After the social gatherings were complete, all participants were invited to a focus group to discuss their perspectives and experiences of the social gatherings. The focus groups were co-facilitated by co-researchers from the CHSS, who asked participants questions about the benefits and challenges associated with attending the social gatherings. Participants provided informed consent and participated in the focus group which were audiotaped and transcribed. All members of the research team participated in the data analysis which involved reviewing transcripts individually and meeting to discuss emerging findings. These analysis meetings

continued for approximately six months, with one meeting a month attended by various members of the research group depending on their schedules. Participant's responses were summarized and organized into several themes which describe the impact of the social gatherings. The theme's will be thoroughly explored in a separate paper that will discuss the importance of understanding the lived experience data and narrative medicine that would provide a profound understanding of the positive impact of the social gatherings. The writers of this paper wanted to focus on the PAR methodology in order to help others interested in this type of research process better understanding of what it means to co-create a PAR methodology, within the HIV community.

High Touch Relationship versus High Volume Research

In order to reduce the impact of commodification of the overall research project the researchers and writers of this paper have chosen to briefly outline the main themes that arose from the focus groups. The in-depth understandings are currently being thoroughly developed within the safety of the high touch peer researcher relationships that best support the review of this information. This brief overview of the understandings from the social gatherings gives the readers of this information insight into how high touch and lower volume research can provide insight into how social relationships can reduce health inequality (Liberzon & Abelson, 2016; Sayed et al., 2015). The social gatherings created a different atmosphere for the participants to be a part of. The relationships that were developed between the peer-researchers and the HIV community participants became the agent of social change. These relationships in the community framed the experiences that were organized by the peer coordinators as many of the social gatherings included taking participants into nature or learning a new activity. Attending functions in different locations helped to get the participants motivated to meet new people and fight stigma and discrimination around HIV. Many people living with HIV experience stigma and discrimination (Peretti-Watel, 2007). Developing a community of like-minded people that live with HIV can make a positive impact in reducing the impact of bias, discrimination and the oppression that marginalizes people that live with HIV. It also provided an opportunity for peer coordinators to lead by example, as successful role models or mentorship for inspiration and to be agents of change through the high touch relationships that they provided to the community.

Getting out of the house, connecting with people and having a great time was part of CHSS's vision for their social gatherings. The whole idea of creating the social gatherings was motivating for members of the peer-researcher community and the participants that wanted to be a part of the social gatherings. Speaking freely with others, without being judged and being yourself was a main experience within the social gathering processes. Being in the society allowed for experiences related to feeling happy, having family type experiences, developing friendships and seeing the benefit of being involved within the HIV community. CHSS peer researchers went the extra mile by excepting everyone that wanted to participate no matter what.

Isolation Versus Connective Relationships

There has been a significant sense of belonging for participants that engaged the social gatherings. For some it was there first time gathering in the HIV community and for others, it was not. Many participants awaited the gatherings as they wanted to get away from clinical settings. The participants wanted to get outside of the healthcare system and community agencies that bind them to their HIV care. The idea of fellowship and gathering brought people into a relational dynamic that created a lasting emotional experience for many weeks after the

event. This relational impact could have lasting neurobiological changes that would reduce the traumatic experience of being discriminated against and being alone (van der Kolk, 2014; Perry & Winfrey, 2021). Some participants found that being invited to the gatherings by the peer-researchers allowed them to feel valued and important.

One participant identified that he was extremely isolated. He clearly identified that “I normally would not go out at all” (male participant). The gatherings became his way of socializing with peers, even though he did not talk a lot, he felt like he belonged. Some gatherings were outdoors which for some participants in the gatherings was empowering as they had not had the chance or were too isolated to be in nature with others. This preplanned experience offered them a location to gather, transportation when needed, opportunities to walk around with people or on their own and exploring venues in Calgary and surrounding area that would be safe, adventurous, and engaging. The diversity of participants was a surprise for some. There was a significant intersectionality of class, diverse gender orientation, age, ability, and many other visible and invisible differences.

One community participant pondered how diverse the participants were in relation to the various social gatherings that he attended. He said, “it was interesting to see to people outside of my social group. It was an eye opener to see the people, who came together” (male participant). The mixing of people and experiences decreased the significance of isolation that many people might feel in their lived experience of living with HIV. Due to the social stigma that many persons experience, they might not engage social experiences that would normally have them engaging with their peers in the community, their workplaces and other social experiences that would help them develop strong social networks.

Mental Health and the Lived Experience

Many members described living with mental health concerns such as generalized anxiety, social anxiety, and depression. They experienced such vulnerability when talking about these topics. The focus groups were both a supportive environment to talk through their experiences of being a part of the gatherings, while also evoking a lot of anxiety as they talked in front of their living with HIV peers. The community participants identified many barriers in relation to experiencing anxiety and depression. One participant discussed how he was extremely impacted by his mental health condition and discussed how he “was afraid to leave the house, due to the anxiety he felt” (male participant).

Another community participant discussed how he would not have come to the gatherings if the peer-researcher had not been positively persistent about his coming to the social gatherings. The participant said that “if it was not for one of the peer-facilitators, they would not have come to the gatherings as she (the peer-researcher) was always contacting with them to make sure they were okay to come” (male participant). Follow-up support was important to recognize subtle behaviors, where individuals were not engaged fully in the activities or under stress. For example, certain individuals may have left the group events, due to their anxieties (or perceived stressors) and a peer-researcher would follow up. More frequent checking “in” by peer-researchers with participants before, during and after events to ensure fuller participation or discovery of any issues became part of the protocols for running a successful social gathering within high touch relationships.

Mental illness has become a co-morbid experience that many people living with HIV experience as a daily burden (Remien et al., 2019). Participants in the social gatherings identified mental health as burdening them as they tried to navigate the experience of living with HIV and the lived experience of living in a world in which they faced oppression, financial pressures, medical uncertainties, social isolation, and a plethora of other lived experience burdens. The benefit of discussing the burden of mental health within the focus group became

a significant contribution for many members that attended the social gatherings. There was a common thread of experience that brought forth the risk of attending the social gatherings, while anxiety and depression prevented them from wanting to enter into social venues as it could be too stressful.

Though the social gatherings did not have a mental health focus, the focus group dialogues brought forth the positive protective factors that the social experiences had given to the gathering members. This high touch relational approach and low volume research would provide the foundational work for trauma-informed practice and the reduction of health inequalities for this population group (Miller, 2019). The commonality of mental health experiences that would be lifted by knowing that they were not alone and that the peer-researchers would contact them multiple times to let them know they were welcomed seemed to provide a significant relief of emotional pressure. Many participants identified that they would not have automatically participated in the social gatherings or focus groups if it had not been for the peer-researchers. A significant number of participants discussed how they felt that “they mattered” (multiple female and male participants) which reinstates the importance of a high touch relational approach which emphasizes the importance of the relationship above all else.

Discrimination and its Impact on the Lived Experience

Many community participants discussed “how CHSS gave them a safe place where they could talk about their lived experience and not face judgement like they do with family and friends” (female and male participants). Members highlighted how there was no judgement by the peer-facilitators as they *live with HIV* as well. A deep sense of safeness emerged in the discussions around the participants feeling that the peer-facilitators were able to understand what they were going through as they all *live with HIV*. The emotional labour that was provided by the peer-researchers for the community was a significant part of the building of safety and trust in the relationships, with the HIV community participants.

In many ways the acceptance within the community formed the foundation for trauma-informed practice, which sought to provide safe spaces and safe relationships for those who might not feel included in society, due to stigma and discrimination. The peer-facilitators became important peer social support leaders, who sought to connect with the participants. They formed safe relationships that brought the participants through the fear of rejection. These social-relational dynamics would keep the lifeline of connection for the social gathering participants.

A few community members discussed how they felt discriminated on a daily basis in society. The CHSS gatherings gave them a safe space to form friendships and enjoy some normal outings with others. Leaving behind the stigma and discrimination that comes with living with HIV in discriminatory society. The act of relationship would bridge them through the isolation. The relationships would also bring them into new experiences that would allow them connection with others, similar feelings were shared with someone in the group, who would understand.

What Are the Inherent Barriers in the Lived Experience of Living with HIV?

Some of the barriers identified by the participants were that people were afraid to come out due to social anxiety, they were afraid to talk in front of people, crowds were frightening for many of them, there was a significant collective concern about being discriminated against, a risk of knowing someone and not knowing anyone and many concerns regarding bringing a family member, partner and or more additional paperwork in order to bring a loved one. The

other concern that was commonly identified by the participants was the issue of financial barriers in relation to travel, cost of attending and fear that they could not attend if they could not afford to travel or pay for activities.

All of the barriers were successfully addressed by the CHSS peer-researchers, who developed protocol that allowed them to contact members before each activity to assure them of location and that all costs were paid including having bus tickets available or a rented vehicle if the activities were outside the city limits. All site locations that were chosen in the city of Calgary for the shared activities were located by a bus route in order to facilitate easy access for the live experience participants. The peer-researchers provided emotional support and fellowship in their high touch relationships as they contacted all participants multiple times in order to reduce anticipatory anxiety prior to the events. At each event lived experience participants were given a number in order to protect their identity. The participants were asked to use the numbers when identifying themselves with each other. Participants were grateful to not have to disclose their personal identity and in time some did use their names which was a choice that they got to make versus the research process making that choice for them.

The peer-researchers spend time talking with each participant in order to reduce anxiety, isolation and stigma issues. They would check-in and make sure that lived experience participants did have access to numbers for community resources, if they were living with isolation, financial barriers or any other concerns that they were willing to talk about. Lastly, if the events were later in the day all members were encouraged to co-share their travel experience in order to make sure that no one was going home on their own, specific to safety concerns.

Economic Stewardship vs Medical Economics

The reduction of the financial costs was substantial and provided a lot of emotional relief for the social participants. The financial barrier reduction was due to the funding providing by Mount Royal University (MRU), Faculty of Health, Community and Education which provided \$7850.00 to the first phase of the research project. For the second phase of the research project, which is currently still being facilitated, the research project was given a second research grant of \$5000.00 by MRU. The money provided through the funding was meticulously accounted for by the peer researchers and the MRU researchers. It allowed the participants to benefit from the social gatherings at no cost to themselves. The participants themselves did receive a small stipend that recognized the participation and time that they gave to the gatherings and focus groups. The overall positive impact of psychosocial outcomes for people living with HIV is enhanced by peer-support (Dennis, 2003; Peterson et al., 2012) and the reduction of financial barriers allowed the community benefit from the social support (Greer & Buxton, 2016).

Peer support shows significant positive impact for people living with HIV including, increased emotional well-being and medical outcomes (Dennis et al., 2009; Funck-Brentano et al., 2005). The peer-researchers were given a full stipend for their expertise and contribution of work towards the development of the social gatherings, the actual work of attending and supporting their peers to attend as well as follow-up administrative and financial record keeping that was required for the funding from MRU. The importance of financial compensation, aligning with the financial requirements of MRU were critically evaluated and implemented in the best interest of the peer-researchers (Ibáñez-Carrasco et al., 2019). The peer-researchers were grateful for the financial generosity of MRU as it allowed them to feel valued in their contributions to their community.

The record keeping and administration requirements also created a significant amount of mental stress as for some peer-researchers. For the peer-researchers the requirements of

being responsible to the university seemed daunting and overwhelming at times. The responsibility that peer-researchers carry can be exhausting and needs to be recognized by university partnerships (Ibáñez-Carrasco et al., 2019). The settings for the gatherings were diverse and inclusive, the social situations were within various settings in and around the city of Calgary. This diversity of settings allowed participants to experience their city, while also recognizing that some members would only choose certain locations, due to having fears and uncertainties about some activities, their locations or other people that might be at certain experiences.

Acceptance and Knowing that “WE” Matter

Many community members were finding new ways to talk about their feelings in relation to their lived experience. For some community members living with HIV is not talked about in their cultural community, with their families and/or with friends. One participant was able to sort through how much appreciation he had in relation to be accepted as a person *living with HIV*. He said, “I feel grateful that I was able to come and not worry about my status” (participant).

There was a common theme for participants that being able to attend the gatherings and not worry about their status and/or people judging them helped them feel less stressed, more included and valued as a member of society. This trauma-informed practice of developing high touch relationships would foster the ongoing sense of community that participants would identify as being key to all relational interactions. The experience of not worrying about people knowing their status was important in order to help participants feel like they belonged in their community. The idea that other members at the social gathering also lived with a HIV positive experience created a new sense of freedom from the discrimination that many experienced on a daily basis.

Some participants had been living with HIV across the lifespan which could include many years of lived experience. Some were newly diagnosed, and some were living with for most of their lives. Participants felt accepted as being long-term survivors or those, who were newly diagnosed or those who had lived with for a shorter period of time. The gatherings were socially focused which allowed for people to be active participants in the activities that were a part of the gatherings.

Understandings that Provide Narrative Medication

Future social gatherings would look to understand the barriers that those who did not come out might be experiencing. There was a gap in academic and community-based practice prior to the research project of what was known about creating a social gathering versus a peer support, community-based research project. The space in the research was where the CHSS peer researchers sought to better understand how the social gatherings would become the catalyst for relational-social change that could create barrier-free social gatherings, increased emotional wellness and decrease stigma and isolation for HIV community members.

The limitations for people living with HIV and not being invited could be embedded in oppression that would relate to their not having access to communication technology such as a computer, phone or being extremely marginalized from the HIV community as a whole became a significant understanding. This limitation was addressed as adequately as possible, during the research by offering high touch relationships versus high volume research tactics such as quantitative data expectations that include numbers and percentages. Moving away from data driven outcomes that justify research dollars and commodify the process of community-based research projects such as this one. The peer researchers were agents of social change as they

advocated for the importance of high touch relationships and the stewardship that was needed to find community participants that might not be engaged in any sort of support service. There might be people living with HIV that felt that they would not be accepted and did not answer the advertisement that was in the community that offered a location, time and contact for the group. This act of seeking to find those, who might not be represented was important for the overall community. The peer-researchers sought to identify if they had done enough to find marginalized members that were not as visible in the community.

The focus groups brought significant narrative understanding about the positive impact that the social gatherings could have for the HIV community members and the peer-researchers themselves. The social narrative that was created during the social gatherings continued to be talked about in the focus groups. The increase in feeling like they belonged, they mattered and that they were a part of a community of people living with HIV and seeking to live well. This information is extremely important not just for the HIV community but for those who seek to help them, support them and advocate for better services, barrier free services and a just and non-discriminatory world.

The final results of the focus groups will be shared in future papers as they carry the lived experience wisdom that was gathered through the focus group format. The privilege of this information is being held by the peer and academic researchers in high touch relationships that protect the practice of its understanding in a safe and non-commodified way. The research team and the HIV community have enjoyed the privilege of writing this first paper for their audiences understanding and value the time that the editors and readers will give to supporting and valuing its understandings.

References

- Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal of Epidemiology and Community Health*, 60(10), 854–857. <https://doi.org/10.1136/jech.2004.028662>
- Bradbury, H. (Ed.). (2015). *The Sage handbook of action research* (3rd ed.). Sage.
- Brezing, C., Ferrara, M., & Freudenreich, O. (2015). The syndemic illness of HIV and trauma: Implications for a trauma-informed model of care. *Psychomatics*, 56(2), 107-118. <https://doi.org/10.1016/j.psych.2014.10.006>
- Canadian AIDS Treatment Information Exchange. (2018). *Practice guidelines in peer health navigation for people living with HIV*. <https://www.catie.ca/en/peernavigation-guidelines#practice>
- Choi, S. K. Y., Boyle, A., Cairney, J., Gardner, S., Collins, E. J., Bacon, J., & Rourke, S. B. (2016). Adequacy of mental health services for HIV-positive patients with depression: Ontario HIV treatment network cohort study. *PLoS One*, 11(6), e0156652. <https://doi.org/10.1371/journal.pone.0156652>
- Collins, E., Cain, R., Bereket, T., Chen, Y. Y., Cleverly, S., George, C., Hayes, P., Jackson, R., Layman-Pleet, D., Li, A., Prentice, T., Taylor, D., & Travers, R. (2007). *Living & serving II: 10 years later - The involvement of people living with HIV/AIDS in the community AIDS movement in Ontario*. The Ontario HIV Treatment Network. https://ohntn.on.ca/Documents/Publications/living_serving_report_April07.pdf
- Dennis, C. L. (2003). Peer support within a health care context: A concept analysis. *International Journal of Nursing Studies*, 40(3), 321-332. [https://doi.org/10.1016/S0020-7489\(02\)00092-5](https://doi.org/10.1016/S0020-7489(02)00092-5)
- Dennis, C. L., Hodnett, E., Kenton, L., Weston, J., Zupancic, J., Stewart, D. E., & Kiss, A. (2009). Effect of peer support on prevention of postnatal depression among high-risk women: Multisite randomised controlled trial. *British Medical Journal*, 338, a3064.

- <https://doi.org/10.1136/bmj.a3064>
- Emlert, C. A., Brennan, D. J., Brennedstuhel, S., Rueda, S., Hart, T. A., & Rourke, S. B. (2013). Protective and risk factors associated with stigma in a population of older adults living with HIV in Ontario, Canada. *AIDS Care*, 25(10), 1330-1339. <https://doi.org/10.1080/09540121.2013.774317>
- Fals-Borda, O., & Rahman, M. A. (1991). *Action and knowledge: Breaking the monopoly with participatory action research*. Apex Press.
- Flicker, S., Travers, R., Guta, A., McDonald, S., & Meagher, A. (2008). Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Urban Health*, 84(4), 478-493. <https://doi.org/10.1007/s11524-007-9165-7>
- Freire, P. (2000). *Pedagogy of the oppressed* (30th anniversary ed.). Continuum.
- Funck-Brentano, I., Dalban, C., Veber, F., Quartier, P., Hefez, S., Costagliola, D., & Blanche, S. (2005). Evaluation of a peer support group therapy for HIV-infected adolescents. *AIDS*, 19(14), 1501-1508. doi: 10.1097/01.aids.0000183124.86335.0a
- Greer, A. M., & Buxton, J. A. (2016). *A guide for paying peer research assistants: Challenges and opportunities*. Pacific AIDS Network.
- Gibson, K., Rueda, S., Rourke, S., Bekele, T., Gardner, S., Fenta, H., & Hart, T., (2011). Mastery and coping moderate the negative effect of acute and chronic stressors on mental health related quality of life in HIV. *AIDS Patient Care and STDs*, 25(6), 371-381. <https://doi.org/10.1089/apc.2010.0165>
- Ibáñez-Carrasco, F., Watson, J. R., & Tavares, J. (2019). Supporting peer researchers: Recommendations from our lived experience/expertise in community-based research in Canada. *Harm Reduction Journal*, 16(55), 1-5. <https://doi.org/10.1186/s12954-019-0322-6>
- Kaufman, J. (2005). China: The intersections between poverty, health inequity, reproductive health and HIV/AIDS. *Development*, 48, 113-119. <https://doi.org/10.1057/palgrave.development.1100187>
- Kimjin Traver, E. (2004). A chaotic dance of cultural competence: A participatory oral history project with immigrants and refugees. *Social Work with Groups*, 27(2-3), 3-21. doi:10.1300/J009v27n02_02
- Liberzon, I., & Abelson, J. L. (2016). Context processing and the neurobiology of post-traumatic stress disorder. *Neuron*, 92(1), 14-30. <https://doi.org/10.1016/j.neuron.2016.09.039>
- Marzialli, M. E., Card, K. G., McLinden, T., Closson, K., Wang, L., Trigg, J., Salters, K., Lima, V. D., Parashar, S., & Hogg, B. (2020). Correlates of social isolation among people living with HIV in British Columbia, Canada. *AIDS Care*, 33(5), 566-574. doi: 10.1080/09540121.2020.1757607
- Miller P. (2019). Interpersonal violence and HIV: The importance of trauma-informed universal responses. *International Journal of AIDS*, 1(1),1-5.
- Oliver, B., Samson, K., Norris, D., John, E., Olaniyan, F., Berezowski, K., Ashaba, R., Asselin, G., Bagnai, J., Bamurekye, S., dela Cruz, A., Hayward, C., Herrera, A., Hill, N., Pearl, C., Randall, M., Van Tassel, B., Visser, F., & Woldermaria, B. (2020). *Preliminary findings from the Alberta stigma index survey*. The REACH National HIV Stigma Community of Practice, Online.
- Ontario HIV Treatment Network. (2010). *Rapid review response: The use of facilitated peer support group model for people living with HIV*. <https://www.ohtn.on.ca/hiv-research-and-interventions-browse-by-resource-type/>
- Peterson, J. L., Rintamaki, L. S., Brashers, D. E., Goldsmith, D. J., & Neidig, L. (2012). The forms and functions of peer social support for people living with HIV. *Journal of*

- Associate Nurses AIDS Care*, 23(4), 294-305. doi: 10.1016/j.jana.2011.08.014.
- Peretti-Watel, P., Spire, B., Obadia, Y., Moatti, J. P., & VESPA Group. (2007). Discrimination against HIV-infected people and the spread of HIV: Some evidence from France. *PLoS One*, 2(5), e411. <https://doi.org/10.1371/journal.pone.0000411>
- Perry, B. & Winfrey, O. (2021). *What happened to you? Conversations on resilience, trauma and healing*. Flatiron Books.
- Remien, R. H., Stirratt, M. J., Nguyen, N., Robbins, R. N., Pala, A. N., & Mellins, C. A. (2019). Mental health and HIV/AIDS: The need for an integrated response. *AIDS (London, England)*, 33(9), 1411. <https://doi.org/10.1097/QAD.0000000000002227>
- Rintamaki, L. S., Davis, T. C., Skripkauskas, S., Bennett, C. L., & Wolf, M. S. (2006). Social stigma concerns and HIV medication adherence. *AIDS Patient Care STDS*, 20(5), 359-368. doi: 10.1089/apc.2006.20.359.
- Sayed, S., Iacoviello, B. M., & Charney, D. S. (2015). Risk factors for the development of psychopathology following trauma. *Current Psychiatry Reports*, 17(8), 612. <https://doi.org/10.1007/s11920-015-0612-y>
- Siemienuk, R. A., Miller, P., Woodman, K., Ko, K., Krentz, H. B., & Gill, M. J. (2013). Prevalence, clinical associations, and impact of intimate partner violence among HIV-infected gay and bisexual men: A population-based study. *HIV Medicine*, 14(5), 293–302. <https://doi.org/10.1111/hiv.12005>
- UNAIDS. (1994). *The Paris declaration*. https://www.unaids.org/en/resources/documents/2014/20141201_GIPAprinciple
- UNAIDS. (2017). *Confronting discrimination: Overcoming HIV-related stigma and discrimination in health-care settings and beyond*. <https://www.unaids.org/sites/default/file>
- van der Kolk, B. A. (2014). *The body keeps the score: Brain, mind, and body in the healing of trauma*. Viking.
- Wallerstein, N., Duran, B., Oetzel, J. G., & Minkler, M. (2017). On community-based participatory research. In N. Wallerstein, B. Duran, J. Oetzel, & M. Minkler (Eds.), *Community-based participatory research for health: Advancing social and health equity*. Wiley.

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 Psychologist. Her second PhD. research focus is on the role of self-determination in the healing of trauma across the lifespan. Dr. Patricia Miller is a collaborative academic researcher that worked with CHSS peer researchers on this participatory action research project. Correspondence regarding this article can be addressed directly 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. Correspondence regarding this article can also be addressed directly to: boliver@mtroyal.ca.

Ken LaPointe 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 to advance 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. Correspondence regarding this article can also be addressed directly to: kenneth.d.lapointe@shaw.ca.

Kim Samson 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. Correspondence regarding this article can also be addressed directly to: kimba44@live.ca. 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.

Kate Berezowski is a graduate of University of Calgary, Master of Medical Science program and is a student of Mount Royal University, Social Work Diploma program. She currently serves as research coordinator on a variety of community-based research projects. Correspondence regarding this article can also be addressed directly to: kbere364@mtroyal.ca.

Kirsten Nelson is a graduate of the University of Calgary, Master of Social Work program. Kirsten is an RSW and works as a clinician in Calgary. She dedicates her time to working with those who are experiencing grief and loss, and mental health issues. Kirsten has a passion for widening academics and research in the field of Social Work. Correspondence regarding this article can also be addressed directly to: Kirsten.M.Nelson@outlook.com.

Kevin (chose not to use his last name, due to wanting to keep some anonymity) is living with HIV. He started volunteering with multiple groups including HIV Community link where he assisted newcomers to Canada and with the CHSS as a Peer Researcher. He started volunteering and supporting the HIV Community long before being diagnosed and will pursue his passion to help fellow newcomers and people living with HIV as long as he is able to. Kevin is using his background knowledge working in immigration related fields and his knowledge as a business owner to assist the group. He is also one of the financial donors to the group helping to provide some of the required funds to run this organisation. Kevin has been involved first as a participant and then as a board member. As a board member he gets to use his legal knowledge and help guide the association through some of the legal requirements and assist with auditing the financials of the association. Kevin has also assisted with developing covid protocols that meet and exceed the requirement at the time of the

creation of said protocols and assisted in the planning and deployment of some of the events. Kevin has also done some peer 1-1 support.

Acknowledgements: We would like to thank all of the people that participated in the social gatherings. Their participation helped us to understand the importance of providing a safe, accepting and barrier free space to gather and explore the meaning of *living beyond HIV-focused stigma*, while reducing isolation.

Copyright 2021: Patricia M. Miller, Brent Oliver, Kenneth Lapointe, Kim Samson, Kate Berezowski, Kirsten Nelson, Kevin anonymous, and Nova Southeastern University.

Article Citation

Miller, P. M., Oliver, B., Lapointe, K., Samson, K., Berezowski, K., Nelson, K., and Anonymous, K. (2021). High touch research: Building community for those living with HIV. *The Qualitative Report*, 26(9), 2837-2850. <https://doi.org/10.46743/2160-3715/2021.4857>
