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## Understanding Lived Experiences of Stigma for People Living with HIV: A Community Based Participatory Research Study

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## Understanding Lived Experiences of Stigma for People Living with HIV: A Community Based Participatory Research Study

### Abstract

The goal of this project was to better understand the experiences and impacts of HIV stigma and discrimination on people living with HIV and to co-create knowledge that has the potential to challenge existing stigma within the healthcare, social services, and public policy sectors in the province of Alberta, Canada. We employed community-based participatory research and a mixed methods design (survey methods and qualitative interviews) to address these questions. An online survey was completed by 148 people living with HIV and semi-structured interviews were conducted with an additional 20 participants. The research findings have been conceptualized within a social ecological model. The four main categories that emerged from the data included personal level factors attributed to HIV stigma, interpersonal factors related to HIV stigma, community factors related to HIV stigma, and HIV stigma in systems and institutions. Within each ecological domain we highlight the strengths and coping strategies people living with HIV identified in the study. Results will be of interest to health researchers and HIV service providers.

### Keywords

HIV, stigma, discrimination, community-based participatory research

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## Understanding Lived Experiences of Stigma for People Living with HIV: A Community Based Participatory Research Study

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The goal of this project was to better understand the experiences and impacts of HIV stigma and discrimination on people living with HIV and to co-create knowledge that has the potential to challenge existing stigma within the healthcare, social services, and public policy sectors in the province of Alberta, Canada. We employed community-based participatory research and a mixed methods design (survey methods and qualitative interviews) to address these questions. An online survey was completed by 148 people living with HIV and semi-structured interviews were conducted with an additional 20 participants. The research findings have been conceptualized within a social ecological model. The four main categories that emerged from the data included personal level factors attributed to HIV stigma, interpersonal factors related to HIV stigma, community factors related to HIV stigma, and HIV stigma in systems and institutions. Within each ecological domain we highlight the strengths and coping strategies people living with HIV identified in the study. Results will be of interest to health researchers and HIV service providers.

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Globally, the human immunodeficiency virus (HIV) is recognized as a major public health issue, having claimed more than 40 million lives (WHO, 2022). The World Health Organization (WHO) estimated in 2021 that 1.5 million people acquired HIV, more than 38 million people were living with the virus, and that close to 650,000 people died from HIV-related causes (WHO, 2022). HIV is a complex and persistent medical and social issue and research is limited regarding how individuals living with HIV experience stigma and discrimination. This study aimed to address this knowledge gap, by exploring this issue further.

Stigma and discrimination have been closely connected to the HIV epidemic in Canada since the first cases were diagnosed in 1979. Although medical treatment has since reframed HIV as a manageable episodic illness, stigma and discrimination continue to shape the lived experiences of those living with and affected by the disease. Stigma is a socially constructed negative attitude or belief that can result in discrimination and unfair treatment (Woodgate et al., 2017). Since the early days of the pandemic, HIV-related stigma has involved labeling, stereotyping, status loss, discrimination, and human rights violations (Heckman et. al., 2002; Link & Phelan, 2001). In addition, it has been linked to mental health issues, depression,

anxiety, and suicidal ideation among those living with the illness (Armoon et al., 2022). Typically grounded in fear, HIV-related stigma and discrimination are closely associated with misinformation about how HIV is transmitted and judgement towards specific social groups that are disproportionately affected by HIV, including gay men, people who use injection drugs, people from endemic countries, and Indigenous peoples (Heckman et al., 2002). Subsequently, HIV stigma intersects with homophobia, racism, sexism, and other forms of discrimination, creating barriers for people living with HIV (Logie et al., 2011).

HIV stigma has had a profound impact on the health, wellbeing, and quality of life of people living with the illness. This has been the case for over forty years, a period within which there has been little improvement. A range of research studies have documented negative experiences, adverse impacts, and barriers associated with HIV stigma. These include rejection from family and community members, social isolation, discrimination by social and healthcare providers, experiences of violence, and discrimination in employment settings (Bogart et al., 2008; Marziali et al., 2020; Reinius et al., 2021; Schuster et al., 2005). Multiple large cohort studies conducted with people living with HIV established that stigma continues to be associated with diminished health-related quality of life and poor outcomes in the areas of physical, psychological, and social functioning (Marziali et al., 2020, Preau et al., 2007).

Recognizing these serious impacts, many people living with HIV are actively challenging the multiple forms of stigma they encounter and empowering themselves in the process. Recently, research has begun documenting the strengths and resiliency factors essential to coping successfully with HIV-related stigma. These include the social and personal resources that moderate the relationship between stigma and health. Research in this area has demonstrated that having a close confidant and receiving social support are significantly correlated with reduced HIV stigma (Emler, 2005). Additionally, studies suggest that social support, coping, skill development, and self-efficacy may reduce the impact of HIV stigma (Dulin et al., 2018; Ma, Chan & Loke, 2018). However, resiliency studies often fail to account for the broader social contexts that shape the experiences of people living with HIV. For some time, it has been clear that people living with HIV face multiple adversities at the interpersonal and community levels and that more information about intervention at these levels is important in supporting positive outcomes despite these adversities.

Given the identified gaps in knowledge related to HIV stigma, the goal of this study was to better understand the experiences and impacts of HIV stigma and discrimination for people living with HIV in Alberta, Canada and to co-create knowledge that would challenge existing stigma within the healthcare, social services, and public policy sectors. We employed community-based participatory research and a mixed methods design (surveys and qualitative interviews) to address these questions. Our research team was diverse and included people living with HIV, health and social service providers, AIDS service organizations, academics, and community members from across Alberta. Community partners involved in conducting the research represented several organizations including The SHARP Foundation, The Centre for Sexuality, HIV Edmonton, HIV Community Link, and the Alberta Community Council on HIV. As academics, community service providers, and activists, we had a shared history in addressing HIV issues through community-based participatory research. HIV stigma and its impact had been a documented need and research priority that had received little attention in our communities. We initiated this collaborative project as a response to this community need and in the hopes that our efforts would lead to greater awareness and social change.

### **Methodology**

We employed a mixed methods approach to explore how HIV stigma and discrimination were experienced by people living with HIV in Alberta, Canada. This approach

was employed as it was considered the best methodological fit to address the phenomenon under study. Based upon a pragmatic worldview, a mixed methods design is particularly useful when quantitative or qualitative data alone cannot sufficiently address the research questions posed (Creswell & Creswell, 2018). A mixed methods approach can assist with triangulation of multiple data sources and can be useful when there is a need to explain initial results that will inform the subsequent phase of a research study (Creswell & Plano Clark, 2018). As a result, the research team determined that participants' perspectives would be best represented with information in both numerical and narrative formats.

### **Community-Based Participatory Research**

Our project was part of a national study with the goals of implementing the HIV Stigma Index in Canada and gathering data on how stigma and discrimination impact the lives of people living with HIV (Friedland et al. 2018). We utilized a community-based participatory research (CBPR) approach, a form of research that emphasizes equity, participation, social action, and the elimination of health and social disparities. Key principles underlying CBPR guided our research, most notably community partnership, promotion of co-learning, capacity building, shared leadership, and the active dissemination of knowledge to all partners (Wallerstein et al., 2017). We applied a participatory approach to the study to ensure that the data generated were useful and of benefit to people living with HIV and their communities. The inter-disciplinary and cross-institutional composition was intentional in that we wanted to ensure that each research partner had a voice in the design and delivery of the study. Subsequently, people living with HIV provided leadership at all stages of the research. This included identification of the research questions, participant recruitment, data collection, data analysis, and knowledge translation and dissemination. Seven people living with HIV contributed to the study as peer researchers: consulting on research methods, recruiting research participants, collecting, and analyzing data, and conducting knowledge translation activities.

### **Research Methods**

We employed an explanatory sequential design whereby quantitative data collection and analysis occurred first followed by qualitative data collection and analysis (Creswell & Creswell, 2018). Because this project was part of a Canada-wide study, the *People Living with HIV (PLHIV) Stigma Index*, was used to gather information on how stigma and discrimination impact the lives of people living with HIV in Alberta. The *PLHIV Stigma Index* was developed to be used by, with, and for people living with HIV. First launched in 2008, the tool was created by the International Community of Women Living with HIV (ICW), the Global Network of People living with HIV (GNP), and United Nations AIDS (UN AIDS). The tool is centered upon underlying principles that locate people living with HIV at the center of the research process. Following a standardized protocol for implementing the index, people living with HIV drive how the study is designed, how information is collected, and how data is analyzed and used (Friedland et al., 2018; Global Network of People Living with HIV, 2022).

Due to the cross-institutional and community-based approach used to implement this study the research team consisted of five representatives from four Alberta-based post-secondary institutions; three representatives from community-based organizations working in this space; and seven peer researchers, trained to administer the survey and conduct in-depth interviews. The study was approved by the Human Research Ethics Board (HREB) at Mount Royal University and the University of Calgary. Funding was provided by the CIHR Centre for REACH and the Public Health Agency of Canada.

**Survey Instrument.** The first phase of this study included the development and distribution of the survey to the population of interest: Albertans living with HIV. The research team and peer researchers guided the development of the survey tool that was used to measure and assess the level of stigma and discrimination experienced by people living with HIV in Alberta. Numerous information sources were used in the development of the survey, including the *People Living with HIV (PLHIV) Stigma Index*, which is an international standardized tool developed by the Global Network of People Living with HIV (Friedland et al., 2018). The index was designed by and for people living with HIV and has been completed by more than 100,000 people in over 100 countries with more than 1,600 people trained as interviewers and peer researchers. (Global Network of People Living with HIV, 2022).

The quantitative phase of the research was guided by the research questions, “what is the nature, extent, and characteristics of the stigma experienced by people living with HIV in Alberta?” and, “what factors co-exist with HIV stigma and serve as barriers or facilitators to health for people living with HIV?” The survey included externally validated quantitative scales to measure types of stigmas, health risks, and protective factors. These included the following scales: the HIV Stigma Scale (Bunn et al., 2007), the Anticipated Stigma Scale (Earnshaw et al., 2013), the Patient Health Questionnaire (PHQ-9), Drug Use Questionnaire (DAST-10), Alcohol Use Disorders Identification Test (AUDIT-10), the Connor-Davidson Resilience Scale (CD-RISC), the Medical Outcomes Study Social Support Scale (MOS-SSS), the HIV Treatment Adherence Self-Efficacy Scale (Johnson et al., 2007), the Medication Adherence Scale (Wilson, 2016), and the Health Care Empowerment Inventory (Johnson et al., 2012). The survey was piloted with people living with HIV who were affiliated with a partner organization; however, no changes were made to the survey instrument which featured 127 open and closed questions.

**Participant recruitment.** To participate in the survey, participants were required to identify as an adult living with HIV and live in the province of Alberta. Due to the nature of the research study and the specific background and experiences required to participate, we used a snowball sampling approach to recruit participants to complete the cross-sectional questionnaire. Snowball sampling is a non-probabilistic sampling method in which initial participants assist in the recruitment of future informants by leveraging their networks to identify individuals who meet the eligibility criteria of a study (Trochim & Donnelley, 2008). It is a recommended approach for studies in which potential participants may be drawn from “hidden” populations, such as the participants targeted in this study: people living with HIV residing in Alberta. (Trochim & Donnelley, 2008).

Recruitment was led by seven peer researchers who shared information about the survey online and across their personal and professional networks. Additionally, our team conducted outreach to regional community groups, non-profit agencies, and AIDS service organizations to ensure a broad sample was achieved. We conducted in-person recruitment on-site at several partner agencies and support to complete the survey was provided by peer researchers to better reach people living with HIV who may not frequent online networks. Special effort was made to connect with people living with HIV from minority groups such as new Canadians, people from diverse ethnocultural communities, and people living in rural areas of the province.

To facilitate survey completion, peer researchers met in person with each research participant, posed all survey questions, and recorded participant responses on a tablet computer. Completed surveys were directly uploaded to an online database using Qualtrics software. All participants who completed the survey received \$50.00 cash as compensation for their time. The survey remained open for a period of six months from October 2019 to March 2020 and 148 people living with HIV from Alberta participated.

**Qualitative Interviews.** In the second phase of the study, we conducted in-depth qualitative interviews. Preliminary results from the survey were analyzed by the research team to learn about participant responses, identify gaps in the data, and inform the development of the interview guide. Based on these ongoing discussions, the research team and peer researchers collaborated in developing specific research questions guiding this phase of the research. These included, “what strengths and coping strategies are effective in managing HIV stigma for people living with HIV in Alberta?” and, “what factors contribute to resiliency for people living with HIV as they encounter HIV stigma?”

For this phase, purposeful sampling was utilized to recruit participants from the survey respondents who had provided consent to be contacted again for an interview. Purposeful or convenience sampling is a technique used to collect samples that meet the inclusion criteria. It involves the recruitment of individuals who are accessible, available and have experienced the phenomenon under study (Creswell & Plano Clark, 2018). Of the 148 individuals who completed the questionnaire, 70 indicated they were prepared to participate in an interview. From this pool of respondents, 20 individuals were selected purposefully based on their ability to contribute to emerging themes in the data and to provide diverse perspectives on HIV stigma.

We completed one round of 20 in-depth interviews between November 2020 to January of 2021. Due to COVID-19 restrictions in our region, the interviews were conducted online using Google Meet technology. In three cases where participants did not have access to the required technology, they were able to access the Google Meet session via cell phone. Twenty people living with HIV were interviewed by peer researchers and each participant received a \$50.00 dollar gift card to compensate for their time. Interviews were video/audio-recorded and transcribed for data analysis. To protect the privacy and confidentiality of participants, the files were stored on a secure drive at the university and only the research coordinator, the principal investigator, and the transcriptionist had access to the recorded interview sessions. Additionally, each research transcript was anonymized.

Consistent with community-based participatory research methods, community capacity building was a priority in all phases of the research. Training in survey methods, communication skills, qualitative research, interviewing, research ethics, and informed consent was provided to the seven people living with HIV who served as peer researchers for this study. Peer researchers received training in self-care techniques and regular debriefing. The peer researchers were compensated with an honorarium for each survey and interview completed as well as for all training and meetings attended.

Creswell and Plano Clark (2018) state that qualitative validity is best established by examining the data collected to determine its accuracy, credibility, transferability, and confirmability. For this study, a number of strategies were incorporated into the design to test for validity, which included member-checking, in which the peer researchers met bi-weekly with the research team to discuss and review data as it was collected. At this time any issues or inconsistencies with the data collection tools and protocol were discussed and addressed. Additionally, the study research coordinator reviewed and monitored the online database to ensure the data were accurate throughout data collection activities. The second strategy included was triangulation, in which the Alberta research team met monthly to review data and data collection protocols and additionally met monthly with the Canadian research team to discuss data collection and emergent themes.

### **Sample Demographics**

**Survey Sample.** The Alberta Stigma Index Study generated a total of 148 completed surveys from across the province of Alberta, an area with a population of approximately 4.4 million people. The survey reflected a diverse geographic response with most respondents

(97%) living in the large urban centres of Edmonton and Calgary. The mean age was 49. Ninety-five percent of survey respondents indicated that they were currently taking HIV medication with 80% reporting that they had an undetectable viral load or were virally suppressed.

Overall, the sample was well educated with 52% of survey respondents reporting secondary education, 27% of whom had completed university. Most survey respondents were either unemployed (23%) or receiving disability benefits (39%) as their main source of income. Only 15% of respondents were working full time and 8% reported working part-time. These factors led to relatively low-income levels among the sample, with 46% reporting that they were unable to meet their basic needs in the previous twelve-month period either some or most of the time.

Diverse gender identities and sexual orientations were represented within the survey sample. In describing their gender identity, 63% identified as male, 34% identified as female, and 2% identified as non-binary. When describing their sexual orientation, 58% identified as heterosexual, 30% as gay, 10% as bisexual, 1% as Two-Spirited, and 1% as asexual.

The survey sample was also diverse regarding ethnicity and culture. Fifty-four percent of the survey sample identified as Caucasian, 18% identified as African/Caribbean/Black, 2% identified as Latin, and 9% identified as other. Twenty-nine percent of respondents self-identified as being a member of an Indigenous group. Fourteen percent of survey respondents identified as being a refugee claimant, asylum seeker, or migrant worker.

Survey respondents described a broad range of relational and family situations. For example, 65% reported being single and living alone. Nineteen percent reported being married or in a common-law relationship. Of those who were in a relationship, 47% indicated that their partner(s) is also HIV positive with 44% reporting being in a sero discordant relationship. A majority of respondents (81%) reported having no dependent children.

**Interview Sample.** Twenty respondents were drawn purposively from the survey sample to participate in the qualitative phase of the study. Participants were chosen based on their ability to contribute to emerging themes in the data. Of these participants, eleven were female (55%) and nine were male (45%). Fourteen participants identified as heterosexual (70%), five as gay (25%), and one participant identified as asexual. There was also a strong level of ethnic and cultural diversity within the interview sample. For instance, eleven participants identified as Caucasian (55%), eight identified as African/Caribbean/Black (40%), and one participant identified as Indigenous (5%).

## Data Analysis

The data were analyzed in two iterative stages. For the survey, demographic data and closed questions were descriptively analyzed using Qualtrics data analysis software. Survey participants were not required to answer any questions they were uncomfortable with, thus not all survey questions were answered by all participants. The data was cleaned by a member of the research team and blank responses, “n/a” responses, and “prefer not to answer” responses were removed from the dataset. Descriptive statistics were calculated for all closed questions.

Qualitative data from the surveys and interviews were analyzed using grounded theory coding methods. We drew upon constructivist grounded theory, a form of methodology that assumes a reflexive stance toward research participants and adopts a flexible approach to the method’s core processes of constant comparison, coding, and theoretical sampling (Charmaz, 2008). Data analysis was conducted iteratively as the interviews were conducted with minor revisions made to the interview guide based on emerging data and in consultation with the peer researchers. Qualitative data were uploaded to Excel software and coded for categories and subcategories by two members of the research team who reviewed all transcripts. We began by



conducting line-by-line coding of the data to identify initial codes and properties. This initial phase of coding involved naming each line or segment of the data in order to identify ideas on which to build the analysis (Charmaz, 2014). These two members met frequently to discuss coding, share decision-making, and reach consensus regarding the emerging analysis. Upon completion of most interviews, the research team conducted a second round of coding that involved comparing data with data and identifying gaps in the research findings that could be addressed in subsequent data collection opportunities. Lastly, theoretical coding was conducted of the data which involved conceptualizing how identified categories may relate to each other and be integrated (Glaser & Holton, 1978). Developed categories were charted and relationships between the categories were identified. The analysis was presented to the research team who helped to contextualize the data, identify gaps, and confirm emerging categories and subcategories.

## Results

In this section, we report and discuss findings from the qualitative phase of the study using select survey results to frame and provide context to the categories and subcategories that emerged from the interview data. We chose specific survey results to frame and provide context to the qualitative findings from the study. Consistent with other recent studies on HIV stigma (see dela Cruz, et. al, 2020; Logie et. al, 2011), these findings have been conceptualized within a social-ecological model that acknowledges both the impacts of HIV stigma and factors supporting personal agency in facing discrimination. The findings are summarized below within four main categories that emerged from the data: 1). personal level factors attributed to HIV stigma; 2). interpersonal factors related to HIV stigma; 3). community factors related to HIV stigma; and 4). HIV stigma in systems and institutions. Within each ecological domain we highlight the strengths and coping strategies people living with HIV identified in the study.

### Personal Level Factors Related to HIV Stigma

In the study, participants identified the personal level factors directly involved with their experiences of HIV stigma. These factors were primarily related to participants' knowledge, feelings, attitudes, and self-concept (an idea of the self constructed from the beliefs one holds about oneself and the responses of others) and included several subcategories that described participants' experiences with and impact of stigma as well as the strategies they enacted to cope with and challenge the discrimination they faced on a regular basis (McLeroy et al., 1988).

#### *Personal Impacts*

Survey data demonstrated that respondents held strong beliefs regarding how people view them as individuals living with HIV. For instance, 72% of survey respondents agreed or strongly agreed that most people are uncomfortable around someone with HIV, 70% agreed or strongly agreed that most people think that a person with HIV is dirty, and 78% agreed or strongly agreed that people with HIV are treated like outcasts. Additionally, a range of experiences of HIV stigma and discrimination were reported at the personal level. The most common experiences reported included overhearing conversations that were stigmatizing to people living with HIV in general (66%), being subjected personally to discriminatory remarks (42%), and being harassed or verbally abused (37%). Less frequent but also reported were incidents of physical harassment or abuse due to HIV status (19%), exclusion from social

gatherings (19%), being refused employment or losing a source of income (17%), and blackmail (12%).

During the interviews, participants endeavored to define HIV stigma in their own words and frequently explained what they felt was at the root of their experiences of bias, stigma, and discrimination. Many study participants felt that others treated them differently, judged them, labeled them, made assumptions about them, or otherwise viewed them negatively based on dominant societal opinions about people living with HIV. For example, one interview participant described the common experience of being othered due to their HIV status, explaining, “HIV stigma, to me, means being treated differently, or discriminated simply for living with HIV.” Similarly, another participant shared, “As people started finding out about me, they started looking at me different and kind of smirking.” For many, this included being associated with common stereotypes held about people living with HIV including assumptions that an individual was gay or used drugs.

Study participants frequently saw the stigma they experienced as fear and ignorance perpetuated by others around them. Many participants connected HIV stigma with an enduring lack of knowledge about HIV in society and felt that they were subjected to that ignorance in their daily lives. One young woman described it in this way,

I still get the, “*Oh my God!*” freak out and run away, “*Can I catch it?*” moments too. So that speaks to the fact that there is still a lot of misinformation, still a lot of fear, there is still a lot of stigma in community.

Many participants spoke of the painful emotional impact of experiencing HIV stigma throughout their lives. This caused many to fear for their future and the assumption that HIV stigma would continue to resurface and negatively impact their life course. Each participant expressed this in unique ways and used powerful language to describe their feelings related to the HIV stigma they had encountered. These involved numerous and common experiences of feeling pain and shame, feeling misunderstood, feeling hated, feeling violated, feeling targeted, and being silenced. One participant, a recent immigrant summarized the impact HIV stigma had on her mental health, “I felt very crushed, to be honest with you. Mentally, psychologically, spiritually ... it starts to make you question, what do I do next? Am I doing something wrong here?”

Study participants connected their experiences of HIV stigma with personal loss. They described the life losses they associated with stigma including a general feeling of losing control and power over life. Many of these losses were deeply personal including experiences of losing voice, losing self-respect, losing one’s dreams, and losing a sense of personal agency. One participant captured the impact of these losses, explaining,

I think the whole impact of stigma for me is that it really prevented me from doing some of the things that I would have had the courage to do otherwise. My HIV diagnosis told me not to plan, not to look forward, not to dream, not to expect a future. Unfortunately, I lived my life that way; large parts of my life were lived with, “*I can’t because of this. I can’t because of that.*”

Some participants discussed having a concurrent history of trauma and mental health issues which interacted with their experiences of HIV stigma. For some, this included depression and suicidal ideation. For instance, among survey participants, 68% of respondents reported feeling down, depressed, or hopeless, with 28% reported having suicidal thoughts over the past two weeks. Others described processes whereby they normalized and internalized the HIV stigma they experienced in their life, explaining how they learned to expect it from people

close to them. Several participants acknowledged that they had absorbed stigmatizing assumptions and had come to believe and apply them to themselves, explaining that “stigma is something we kind of hold onto ourselves, right? It is something I hold in my heart myself.”

### *Strengths, Coping, and Resilience*

Despite these profoundly negative impacts, participants also described a range of coping strategies they had developed over time to manage HIV stigma. Specific strategies such as using humor, empathy, and personal faith to cope with HIV stigma were frequently discussed.

Access to accurate information about HIV was also seen as a critical tool in challenging HIV stigma, both for people living with HIV and those close to them. Being informed personally and educating others about HIV were concrete measures participants utilized to deal with stigma among their personal networks. One participant summarized this importance: “Education on HIV is so important because you can’t deal with stigma if you can’t talk about what the disease is and educate people on it.” Some participants limited themselves to educating those close to them while others took on formal roles within an AIDS service organization: strategies they found personally empowering. Regardless, many saw accurate and relevant information about HIV as critical to empowering themselves and others to address HIV stigma. Many participants also reported seeking professional help to deal with the effects of HIV stigma and others described learning to brush it off, getting angry, and becoming an activist as useful coping strategies.

Additionally, many study participants described their ability to learn, grow, and develop resilience as they coped with stigma over the course of their illness. Defined as an interpersonal construct involving successful adaptation to negative life events, this resilience existed on a continuum and was both a product of and a contributor to many participants’ successful coping (Emler et al., 2010). Survey respondents identified coping strategies that contributed to their level of resilience in the face of HIV stigma. For example, 79% of respondents reported that they thought of themselves as a strong person often or nearly all of the time, 71% identified that they were able to adapt to change often or nearly all of the time, and 70% indicated that they tend to bounce back after illness or hardship often or nearly all of the time.

A majority of interview participants discussed their capacity to reflect on their experiences with HIV and stigma, develop self-awareness, and gain a stronger sense of self in the face of HIV. For example, one participant spoke of how she built strength over time to better cope with stigma: “Personally I have been on a hill or a mountain of continual learning and adjusting my own approaches or skills on how I tackle this kind of situation.” Many participants spoke of feeling challenged by stigma and eventually empowered as they successfully overcame these adverse situations. This was the case for one female participant who reported, “I have thirty years of lived experience that I have worked through, and it has been bumpy, and rough, and bitchy and miserable and cruel along the way, but it has been joyous and wonderful, and uplifting.” For some, this path towards self-awareness helped them to develop a sense of empathy for others, even those who perpetuate HIV stigma. This was the case for one participant who explained,

I understand that sometimes people are just coming from a place of emotion and fear, and I also try and put myself in the other person’s position and try to understand and be more compassionate about what they are bringing to the table when they bring stigma there and drop it on my lap!

## Interpersonal Factors Related to HIV Stigma

Interpersonal factors related to HIV stigma emerged from both the survey and qualitative findings. These factors involved the relational processes connected to participant experiences of HIV-related stigma. Factors at this level are attributed to social networks, relationships, and interpersonal dynamics (Sallis et al., 2008). Here, participants described two main areas of impact: experiencing HIV stigma in their relationships and the social exclusion they experienced as a result of the HIV stigma they face.

### *Experiencing HIV Stigma in Relationships*

Many participants spoke of the negative impact HIV stigma has had on the relationships in their lives, including among their friendships, families, and romantic relationships. For many participants, the losses due to HIV stigma included friendships and community connections, with some reporting that people rejected and walked away from them or left their lives upon learning of their diagnosis. One participant described these experiences which were common for her, “I have had a lot of people walk away because HIV was the deciding factor in whether somebody wanted to be in my life.” Another participant discussed what happened when a neighbor inadvertently discovered her status: “I had a lady down the street from me, she found out and we got into a huge fight and she was yelling outside saying, “Don’t be around her, she has AIDS!” Facing rejection and stigma from close family members was often described by participants with some describing losing all connection to their families. One participant spoke about the impact of this experience, “I think one of the most impactful things was a family member calling me diseased and disgusting ... just treating me like I was dirty.”

Foremost for many participants was the loss of personal and romantic relationships due to the impact of HIV stigma. For instance, 38% of survey respondents worried that sexual or romantic partners were likely or very likely to look down on them and 40% worried they would be treated differently by romantic partners. Consequently, 58% of survey respondents reported that they had decided not to have sex or engage in sexual relationships at all. This was discussed frequently in the interviews where many participants spoke of losing the opportunity to date altogether and feeling judged for dating or seeking romantic partners. Despite the advances of biological and behavioral HIV prevention strategies, many participants reported still feeling rejected by romantic partners. A male participant shared one experience after disclosing their HIV status to a romantic partner:

You cannot contract it by kissing or going on a date, but she got very upset and very apprehensive, and that was pretty much the end of the relationship. That is pretty much a clear example of the stigma that goes on, and it does ... it sticks with you when you are trying to now pursue the next relationship. You start to question yourself, like what do you do? Do I spend the rest of my life by myself, or do I pursue a relationship or not? So yeah, stigma is definitely there.

Another participant spoke about the judgements they faced from others: “There is the expectation that you shouldn’t date, and people will actively say that, like, “How could you?”

### *Social Exclusion*

One consequence of HIV stigma at the interpersonal level is the prevalence with which social exclusion was experienced by study participants. In the survey, 48% of respondents worried that neighbors and others in the community were likely or very likely to avoid them

while 49% worried they would be treated differently by these people. As a result, 40% of participants reported isolating themselves from their family and friends. Social exclusion was discussed extensively in the interviews where it emerged as a reciprocal and cyclical process whereby participants reported both being excluded due to HIV stigma and isolating themselves as a defense and in order to protect themselves from future stigmatizing experiences. This type of social exclusion was described briefly by one participant, a recent immigrant:

Stigma kind of hurts in my heart a little bit, and it has kept me, I think, stuck and living in my little bubble... They have isolated me. They have made me sad because of the ignorance of the world.

Additionally, many participants acknowledged that they actively avoided building relationships with other people due to HIV stigma and the fear of being judged by others. This was also the case for the following female participant:

When I am being stigmatized by my own people - people who are supposed to be my relatives and close friends who are supposed to be out there for me ... oh my goodness, that one, it hurts. It hurts. So, I keep it to me because I don't want the frustration, so I have decided to keep minimum contact, and I have never gone back to my relative's house... I just made a choice not to make people feel uncomfortable because of my status. So, all I do is I avoid them.

For many participants, this isolation and exclusion was a barrier to accessing needed emotional and social support. Several acknowledged that the social isolation imposed on them by HIV stigma had led to barriers to accessing and providing crucial emotional and social support both informally and formally. For some this was a barrier to accessing supports from community health and social service providers. Additionally, the few participants located in non-urban environments described an added sense of physical and social isolation.

### *Managing Disclosure*

The process of exclusion and self-isolation was closely connected to participant disclosure of their HIV status. Many participants described experiences where their HIV status was disclosed without consent by family members, friends, and in health care settings. These experiences caused them to lose trust in others and worry about how they can control disclosure of their status. For many the burden of disclosure was an added stress connected to stigma and rejection; a fear that they carried with them constantly. In the survey, 65% of respondents indicated that it was difficult to tell people about their HIV infection and 63% reported that they often hide their HIV status from others.

Many study participants reported experiencing no stigma because they had not disclosed their illness to anyone aside from health care providers. This was the case for one participant who explained, "At this point the only thing I can say is I don't share that part of my life with anybody, and so that has basically managed to keep me from experiencing the stigma much." Others confided in a few close people, keeping the circle small to protect themselves. Very few participants had publicly disclosed their status and those who had considered it feared repercussions. For most participants, maintaining close control over disclosure of their illness was an effective measure to protect themselves against stigma and loss. Participants described stigma as an experience of losing control over their lives. Consequently, how they approached disclosure and protecting their status from others in the community was described as a means to take back some control over their lives. Participants

described managing disclosure strategically and setting boundaries around when and where to disclose (both for their own protection and for others).

### *Developing Personal Support Networks*

In addition to managing disclosure, participants discussed other strategies for countering stigma at the interpersonal level. Despite some stigmatizing experiences many participants also cultivated supportive relationships among their friends and family members. Developing a strong personal support network was discussed in the interviews as a critical strategy to buffer against hostility and stigma. For instance, many participants discussed empowering themselves by developing relationships with people who were positive and supportive and letting go of negative or stigmatizing relationships that they saw as unhealthy for them. Participants often identified "friends who know" and talked about feeling safe in relationships with people who knew their status and were supportive. In some cases, these were other people living with HIV, whereby connecting and gaining support from them enabled many to develop confidence and learn and grow from their experiences with HIV stigma. Additionally, families were sites for both experiencing stigma and gaining support. For some, a key supportive family member was often valued as an important buffer against stigma.

### **Community Factors Related to HIV Stigma**

The concept of community resonated strongly with study participants, many of whom expressed a desire to connect with and contribute to the broader community to counter the stigma they faced in society. Community life may involve a psychological sense of community, a means to meeting sustenance needs, political engagement, or simply a gathering of individuals in a particular location (Macqueen et al., 2001).

In the survey, 78% of respondents reported that they were members of a network or support group of people living with HIV. While acknowledging that stigma can be perpetuated through community structures, most study participants valued their community connections and described them as a mediating influence on the various forms of stigma they faced. During the qualitative interviews, participants commonly described community life as a venue for gaining fulfillment and an opportunity to connect with others living with HIV.

The majority of participants described accessing services provided by community organizations and AIDS service organizations, programs that they found supportive in helping them address stigma. Several participants described the benefit that these programs provide. For instance, one female participant described the sense of safety she felt in accessing services at an Aids Service Organization (ASO) and how this was a reprieve from the stigma she often faced: "It is somewhere where you can meet people who are also like you so you don't have to feel awkward or uncomfortable because you're all kind of in the same situation." Another participant remarked, "So those individuals within the group, whether they be staff or clients in an ASO, I get support from that. I get support just from sitting down and having coffee with them and just chatting." The ability to connect in this way and access emotional and social support was seen by many as a critical buffer for HIV stigma.

However, for most, community involvement was not limited to simply accessing services. Connecting within the community was described by many as a reciprocal and active process. Many study participants described a deep engagement in community organizations that involved roles as volunteers, activists, educators, and leaders. Rather than simply being clients, many participants described experiences in community that allowed them to give back by providing outreach, helping others, volunteering, serving as a resource, and actively

building a supportive community. This engagement in community development was effectively described by one participant:

The most important thing is creating community... so you are not alone. Having that net, that support network, and helping teach how to build that. Teaching those basic skills of coping, building our networks, and fostering that, it is so important; so important.

For many participants, being involved in the community in this way provided hope, helped them build confidence and self-esteem, and provided a social support network to challenge HIV stigma.

### *Peer Supports*

Interview participants described a range of interventions they felt were effective in addressing and challenging HIV stigma and discrimination. Peer support programs were frequently described as valuable sources of support that helped individuals reduce social isolation, normalize the illness, and build community resilience in the face of HIV stigma. Peer support is emotional and practical support between two people who share a common experience: in this case, living with and experiencing HIV. Strong relationships developed with their peers provided lasting friendships that persisted beyond the bounds of a support group. They also ensured a safe space to counter stigma, and contributed to an empowered community of people living with HIV. Many interviewees perceived peer supports as providing increased privacy, being less judgmental, and being more confidential than professionalized services. Participants described the benefits of peer support in simple but powerful terms. For instance, one interview participant reported:

It may not be a big deal, just an hour talking about life, but it makes me feel good just to be able to talk to other people who might be going through the same things as me, and that kind of thing makes you realize you are not alone.

Another participant emphasized the power of shared experiences remarking, “every time when you meet with people who are kind of sharing the same thing, you give each other strength, you know.” In an environment where funding for social support is shrinking, some participants voiced disappointment with the lack of professional support available. However, there was also an understanding that peer support was unique and more sustainable and that their peers would always be there for them no matter what.

Participants who were able to overcome the barriers of stigma valued their community networks and connections, describing community life as a venue for gaining fulfillment and an opportunity to connect with others. A developing sense of personal agency frequently existed among study participants. For many, the ability to develop the resources and knowledge to live well despite challenges was created in connection with others and through participating in community life.

### **HIV Stigma in Systems and Institutions**

Social structures and institutions are important sites within which study participants frequently experienced HIV stigma. This level of findings describes how HIV stigma was embedded in the systems and institutions that study participants commonly interacted with

notably health care settings, places of employment, and systems where they encountered intersectional discrimination.

### *HIV Stigma in Healthcare Settings*

The health-care system was most frequently reported as a space where participants experienced institutional stigma. One important area concerned privacy and confidentiality. When responding to the survey, ten percent of participants reported that a health-care provider had disclosed their status without their consent, and 39% reported that they were not sure that their medical records were kept confidential. Additionally, 17% of survey respondents reported that healthcare providers had avoided physical contact with them because of their HIV status. While such perspectives were not shared by the majority of respondents, they are cause for concern as healthcare providers have an ethical and professional responsibility to provide informed, confidential, and unbiased care. As one participant observed, “For me, I find that very disappointing because as a healthcare professional you should know better.”

Survey findings were validated by interview participants who described stigmatizing experiences while receiving care from physicians and other healthcare professionals including at point of diagnosis and while receiving routine healthcare. One interview participant described a recent experience while accessing healthcare:

The anesthesiologist asked me if I was a sex-trade worker because I had HIV. Regardless of whether I was or not it is not appropriate to assume... it is just that underlying stigma and being treated differently when you are just wanting the same care as everybody else, and being treated so different. And it is so uncomfortable.

Some interview participants described lack of knowledge about HIV among healthcare providers and were uncomfortable with the responsibility and burden of having to educate them. Many participants discussed HIV stigma as a barrier to accessing healthcare services and a distinguishing factor in putting off or delaying needed healthcare. In particular, the burden of needing to disclose their status repeatedly was cited as a deterrent as were historic and long-term negative experiences dating back to the early days of the HIV pandemic. This was the case for this interview participant, who recalled, “there are times when I have chosen not to access healthcare just because I don’t want to deal with that.”

In addition to HIV stigma, participants described encountering sexism, racism, and homophobia while accessing healthcare. For many, this was an extra layer of stigma that contributed to making them feel uncomfortable in healthcare settings. One interview participant, a Black woman living with HIV, described her experience with racism while accessing healthcare:

An example is the clinic that I go to, the secretary there, she is Caucasian, and because it is an HIV clinic, me being a Black person, when I walk in, I feel she looks down on me, not only because of the disease, but also because of my skin color. It makes me feel out of place.

Another interview participant described a similar sense of discomfort when healthcare providers made assumptions about their identity: “Yeah, if you go into the clinic and they see me sitting there, they just think immediately that I am a homosexual. You just see how people look at you and you can kind of just feel it, right?”



### *HIV Stigma in Employment*

Employment was the second most commonly mentioned site where participants encountered stigma and systemic discrimination. The majority of survey respondents (79%) had achieved secondary or post-secondary education. Nevertheless, only 15% of survey respondents were employed full-time. For many, their reason for not being in the workplace was due to HIV stigma rather than failing health. Interview participants provided some insight into this, reporting frequent historical experiences of stigma in employment settings. One participant described the discrimination they had experienced from a supervisor, “I honestly could say in my previous workplace just the way a manager talked to me or treated me was very different from how they interacted with other people, and that really sucked.”

Generally, HIV had led to the loss of employment opportunities and been career-limiting for many. In some cases, the discrimination was subtle rather than direct, as described by this study participant: “I know I haven’t had opportunities for work because I know they know. I don’t know, and I can’t say for certain that was why those opportunities weren’t there, but I can say intuitively I feel like that was a thing. You know?” Furthermore, several interview participants reported being fired when employers learned of their HIV status and losing employment opportunities due to stigma. This was the case for one study participant who reported, “I lost a job working in the food industry because I had it and I was fired from my job for HIV.” Others described losing their jobs while they were ill. This caused many to fear for their jobs and led to them being very cautious about disclosing their status at work.

### *Activism and Advocacy*

In addition to HIV stigma, participants described intersectional discrimination including experiences of racism, homophobia, sexism, and stigma in the immigration and legal systems. Many participants described the form and nature of intersectional stigma in Alberta including the belief that stigma is connected to the political climate, encouraged in the community, and that very little has been done to address stigma in the community. This was the case for this participant who commented, “Yeah, I certainly feel impacted by that within our community and throughout the years feel completely discriminated against, and stigmatized. The greater society, it has been like a free pass to do so, which is really sad to me,” and for another who summarized, “Alberta was always called ‘God’s Country’ and HIV is the devil’s work, right? It is as simple as that.”

Despite encountering pervasive stigma within the systems on which they rely for support, many study participants described learning to fight back against stigma as a coping strategy. This was the case for one interview participant who described the importance of challenging the stigma they experienced,

You have to fight back. The only recourse you have is to fight because if you sit and you let that sit inside with you, it will eat you alive and you will become an addict, or homeless, or consumed with fear. It just eats at you, right?

Critical processes of standing up for themselves and others and speaking out against stigma when they encounter or witness it were viewed as important forms of resistance against stigma. For some, becoming an advocate and taking on a formal role as a volunteer or activist was a route to personal and collective empowerment. This was the case for this participant who described their development:

That is when I started speaking in high schools, that is when I found my advocacy voice, that is where I found my need to make change, that is where I became vocal, it is where I became angry, it is where I became passionate. It is where I found me.

Additionally, one participant spoke of learning to be vocal in the face of stigma and defending others: “I don’t sit silent anymore, so when I see someone being judged, or harmed, I don’t sit silent.”

## **Discussion**

Findings from this community-based participatory research study have been conceptualized within a social-ecological model. For this study, an ecological perspective provides a framework that captured the intersecting and mutually-reinforcing nature of the emerging categories as well as provides for detailed analysis of the data at multiple conceptual levels. These levels included personal level factors, interpersonal factors, community factors, and factors embedded in systems and institutions. These results contribute to an expanded contextual view of stigma for people living with HIV and highlight the importance of community, structural level factors, and resilient coping strategies.

At the personal level, participants took the opportunity to identify and define the stigma they frequently faced. Many connected HIV stigma with a general ignorance and lack of knowledge about HIV in society. They spoke of the painful impact of experiencing stigma throughout their lives and over many years. Study participants connected their experiences of HIV stigma with personal loss, a phenomenon they had experienced repeatedly throughout their lives. Participants described how they internalized the HIV stigma they experienced and the feeling that somehow, they carried it inside of them. Similar accounts of internalized stigma have occurred in the research literature on health and stigma and describe how members of a stigmatized group often adopt negative beliefs and feelings they encounter in society (Stangl et. Al., 2019). At the interpersonal level, foremost for many participants was the loss of personal and romantic relationships due to the impact of HIV stigma. Many spoke of losing the opportunity to date altogether as well as feeling judged for dating or seeking romantic partners. These phenomena were closely connected to reciprocal processes of exclusion and self-isolation that were reported by many. Here, participants reported both being excluded due to stigma and isolating themselves as a defense and in order to protect themselves from future stigmatizing experiences.

Participants described interventions they felt would be effective in addressing and challenging HIV stigma. In particular, community-based peer support was frequently described as a valuable source of support that helped reduce social isolation, normalize the illness, and build strength and resilience in the face of HIV stigma. Peer support is emotional and practical support between two people who share a common experience: in this case, living with and experiencing HIV. Peer support programming has been used widely in a variety of chronic health conditions but relatively few of these programs now exist in the HIV community and very little research has focused on their benefits for people living with HIV (Collins et. Al., 2007). Despite the lack of peer support programs in the community, some research has established the efficacy of these approaches in countering the stigma and social isolation so often experienced by people living with HIV. For instance, a systematic review identified that self-help and support groups are effective in addressing stigma and discrimination related to HIV and highlighted peer support as central to effective responses to stigma (Mahajan et al., 2008). This has also been found within the research on HIV stigma conducted in diverse community settings. In a large Canadian study exploring intersectional stigma and discrimination, women

living with HIV reported social networks and peer support as vital coping resources. Their ability to create a forum for sharing their experiences and learning from each other was cited as instrumental in combatting the effects of HIV stigma as well as racism and sexism (Logie, et al., 2016). Based on current evidence, it appears that support for community-based peer programming merits attention as a stigma reduction intervention.

Limitations related to the sampling approach and cross-sectional nature of this study do not permit us to generalize from the survey results or make any conclusions that would apply beyond the local and regional context of the study. The surveys were self-reported which may introduce reporting bias. Additionally, some key identity groups impacted by HIV in Alberta were not included fully in the study due to difficulties in recruitment. Our findings suggest that HIV stigma remains a significant challenge for people living with HIV, particularly anticipated stigma. Additional research on the impact of stigma on diverse groups as well as intersectional factors is an important priority and would contribute to the literature as well as community response.

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### **Author Note**

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