



THE BC PEOPLE LIVING WITH HIV STIGMA INDEX

“Activism is the rent I pay for living on this planet”:
exploring life stories of people living with HIV and their
relationship to major strengths

Madeline Gallard, Paul Kerber, Kajiko Nanami, Darren Lauscher, Lonnie Brezina, Alfiya Battalova, Joanna Mendell, Jennifer Demchuk, Janice Duddy,
Sophie Bannar-Martin, Catherine Worthington

Background

People with Lived Experiences' Strengths in the Face of Stigma is a qualitative study. It is a continuation of the *BC People Living with HIV Stigma Index* study, a survey-based data collection process; we used our findings from the Stigma Index, assessed where we had additional research questions, and created the qualitative interview.

This qualitative study included 20 participants, all people living with HIV. Our intent was to use a strengths-based approach to examine the following research questions: What contributes to major strengths and resilience for people living with HIV? And What makes programs and services work well for people living with HIV?

The study is co-led by Sophie Bannar-Martin (Island Health), Dr. Catherine Worthington (School of Public Health and Social Policy, UVic) and J. Evin Jones and Janice Duddy (PAN). This study is housed at PAN, a provincial network organization that works collaboratively with 40+ member organizations and people working in HIV, hepatitis C and harm reduction across BC. PAN provides workplace training, leadership development, supports community-based research and evaluation initiatives, and helps facilitates a provincial collective impact network. PAN consults with its members across the province to ensure a representative BC-wide voice as it advocates for change in public perception and policies.

This study is guided by an active study team, consisting of people with lived and living experiences, academics and policymakers. Their role is to give us direction on research vision and methodology, to suggest analysis approaches and knowledge mobilization products, as well as review and advise on knowledge mobilization products.

Key Messages We Found:

Taking a strengths-based approach enhanced the richness of interviews. Asking participants to reflect on areas such as strengths and visions for the future made people think more deeply and offer complex reflections that touched on a number of topics, including intersecting identities.

Some participants felt positively about the interview taking a strengths-based approach. One participant noted that it was nice to talk about good things and not all the bad things or things going wrong.

A focus on strengths sometimes resulted in participants' taking a storytelling approach to answering questions – people sometimes contextualize their own strengths within the experiences they have held.

Methods

People With Lived Experiences' Strengths in the Face of Stigma takes an intentional community-based research (CBR) approach. The study was developed on the advice and direction of the active study team to dig into strengths and move away from a deficits-based approach. We also consulted with the study team on our interview guide to examine the language and the order of questions.

Strengths-based, CBR Approach

Participatory data analysis that will involve collectively examining key themes and posing further questions to the data. We will build on this to determine knowledge mobilization activities, including key audiences, messages, and products.

In line with our strengths-based approach, our interview guide allowed for open-ended answers for participants to expand on topics as desired. Questions focused on topics such as: participants' strengths, life experiences, and visions for the future for the community (a world without stigma).

This qualitative study included phone interviews with people living with HIV in BC; the interviewer was also a person living with HIV. We took an intentional approach to provide geographic diversity and connect with participants with identities that are not always well-represented in research.

An initial round of thematic analysis was completed in a data analysis software called Quirkos. A mixed inductive/deductive approach was utilized, and this initial analysis was conducted by a Peer Research Associate (PRA) along with research staff. Existing themes in our code book focused on our research questions (e.g., 'major strengths') and emergent themes were added to the codebook through a collaborative process.

Reflections on Approaches

Key takeaways from the study so far:

1

Questions often led participants to discuss experiences in a storytelling fashion, meaning that they spent time within the interview reflecting on their strengths and life experiences. This was supported by having a person with lived experience leading the interview process. This storytelling painted a broader picture within the interviews than simply asking about bad or negative experiences.

2

Ultimately, a strengths-based approach allowed us to better reach our goals of answering our research questions and supporting participants.

3

The strengths-based approach felt innovative to some participants, as participants were not always used to being asked positive questions. Some participants reflected that it was a nice change to be focusing on the good and asking them about themselves in a positive way. Research staff observed that this approach contributed to the overall richness of interviews as some participants felt more comfortable when being asked about strengths as opposed to weaknesses.

Next Steps

In line with our community-based approach, the next steps for the *People With Lived Experiences' Strengths in the Face of Stigma* will look like:

PARTICIPATORY ANALYSIS

In line with our community-based approach, we will be engaging in participatory analysis in order to ensure that all voices around the table are heard and that we are exploring angles and perspectives that may not be visible to everyone in the group. Using this approach is important as it democratizes analysis and allows the work to continue to be focused on community – being led by community and ultimately being useful and supportive to community.

FURTHER WORK

We will be creating a summary of findings in the coming months that will be posted on the PAN website (paninbc.ca).

We will also continue to support the work happening across Canada in relation to the *People Living with HIV Stigma Index*.

DATA PARTIES

We will be bringing initial findings back to the study team in the form of a data party for review and engagement. A data party is an opportunity for all those engaged in a study (e.g. study team, study leads and community members) to work through data collaboratively and collectively analyze it to identify findings (Hutchinson, 2021). We will also be engaging in a data party to focus on brainstorming knowledge mobilization techniques and products to share out these findings. We hope to achieve a better collective understanding of these data and how they can be shared and useful for community.

Thank you to our study team for their support and insights and to our funder, REACH Nexus.

Sources:

Hutchinson, K. (2021, October 29). You're Invited to a Data Party by Kylie Hutchinson. AEA365. <https://aea365.org/blog/youre-invited-to-a-data-party-by-kylie-hutchinson/>