"HIV is a Story, not Life": Resilience among South Asian Women living with HIV in Canada

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ABSTRACT

Purpose: This study aimed to understand how immigrant South Asian women living with HIV in Canada develop resilience and to identify their self-management strategies. These strategies could be used by marginalised women and can be supported by health providers.

Method: The study participants were eight South Asian women with HIV, living in Ontario, Canada. The women belonged to an urban HIV community organisation. Qualitative methods were used to investigate their experiences. Indepth face-to-face interviews were conducted, utilising a photo/object elicitation technique, to identify the strategies used to develop resilience.

Results: The women were primarily in mid-adulthood (age range 39-60 years) and had lived for many years with HIV (range 8-25 years). Thematic analysis of the interview transcripts revealed three themes characterising strategies for resilience: identifying the need for self-care, maintaining social connectivity, and remaining optimistic.

Conclusion and Implications: With these strategies, the women had cultivated strength and perseverance in adjusting to adversity. Viewing the resilience of South Asian immigrant women living with HIV through a cultural lens could help to understand and facilitate the development of culturally acceptable selfmanagement strategies.

Key words: resilience, South Asian, women, HIV/AIDS, disability

INTRODUCTION

The early provision of antiretroviral treatment has significantly increased the life expectancy of people living with HIV (Yang, Beymer, & Suen, 2019). Individuals living with HIV may experience the premature onset of comorbidities such

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as diabetes, heart disease, obesity, metabolic disorders, stroke, osteoporosis, osteoarthritis, inflammatory arthritis and cancer (O'Brien, Wilkins, Zack, & Solomon, 2010). They can also experience health-related challenges due to HIV infection and the side effects of medications, such as fatigue, diarrhoea, nausea, muscle weakness, decreased muscle mass, stress, depression, lipodystrophy, neurocognitive impairment and peripheral neuropathy (Snowden et al., 2017; Squires et al., 2011). Moreover, an HIV diagnosis itself may impact an individual's psychosocial well-being, in part due to HIV stigma and discrimination which may result in HIV-related disability (Dale et al., 2009; O'Brien, Bayoumi, Strike, Young, & Davis, 2008).

Disability is defined as impairments in body structure or function, activity limitations, and social participation restrictions that influence individual and societal perspectives (Stucki, 2005; World Health Organisation, 2007). The Episodic Disability Framework builds on the International Classification of Function and Disability and was derived from the perspectives of people living with HIV (O'Brien et al., 2008). The Episodic Disability Framework was designed to capture the health-related challenges and potential fluctuations in these challenges that may be experienced by adults living with HIV (O'Brien, Davis, Strike, Young, & Bayoumi, 2009).

The Framework consists of three components - dimensions of disability, contextual factors, and triggers of disability (O'Brien et al., 2008). Dimensions of disability in the Episodic Disability Framework include physical, cognitive and mental-emotional symptoms and/or impairments, difficulties in carrying out day-to-day activities (e.g., household chores), challenges to social inclusion (e.g., employment, personal relationships), and uncertainty or worrying about the future (O'Brien et al., 2008). The contextual factors of disability include intrinsic (e.g., living strategies and personal attributes) and extrinsic factors (e.g., social support, stigma) that may influence the dimensions of disability (O'Brien et al., 2009).

In Canada, South Asian women constitute a small but increasing number of people living with HIV (Haddad, Li, Totten, & Mcguire, 2018). However, their experiences of living with HIV and the resulting disability remain understudied. Understanding the experiences of South Asian women living with HIV is particularly important because they may be more disadvantaged than others who are living with HIV in high-income countries and are embedded in Canadian societal contexts. In South Asian culture, women are gatekeepers of family honour

(Vlassoff & Ali, 2011) and may not disclose their HIV status because of their community's lack of understanding about HIV and the community's tendency to blame and stigmatise women for their HIV status (Hawa, Underhill, Logie, & Loufty, 2018). Immigrant South Asian women who are legally sponsored by their husbands are at an increased risk for intimate partner violence (Ahmad, Driver, McNally, & Stewart, 2009). In addition, economic dependence, residency status, and societal norms such as silence, obedience and subordination, combined with fear of divorce and anxiety about their children's future, may also compromise South Asian women's ability to disclose their HIV status (Finfgeld-Connett & Johnson, 2013; Majumdar, 2013; Zhou, Majumdar, & Vattikonda, 2016). A previous study (Vajravelu, O'Brien, Moll, & Solomon, 2022) demonstrated that South Asian women living with HIV experience intersecting vulnerabilities such as intimate partner violence, gender norms, HIV-stigma, and racism. Little is known about strategies that these women use to cope with day-to-day challenges, and how these are shaped by the individual and social contexts in which they live. Understanding their experiences and coping strategies may provide insights into how South Asian women with HIV develop resilience.

Resilience is a positive adaptation which helps an individual to overcome threatening situations (Earnshaw et al., 2017). Studies examining resilience among people living with HIV suggest that coping strategies such as social support and intrapersonal skills have a positive impact on their psychological well-being (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013). However, there is a dearth of scholarly knowledge on resilience among South Asian women living with HIV in Canada.

Objective

The purpose of this study was to understand and identify the self-management strategies used to develop resilience among immigrant South Asian women living with HIV in Canada. Their coping strategies could be followed by marginalised women and can be supported by health providers.

METHOD

Study Design

An interpretive phenomenological approach was adopted to explore the lived experiences of immigrant South Asian women living with HIV. Interpretive

phenomenology focuses on describing the experiences of individuals and how these influence the choices they make (Lopez & Willis, 2004; Pietkiewicz & Smith, 2014).

Sample Size

For a phenomenological study, Morse (2000) recommends a sample size that is small, yet provides an in-depth understanding of participant experiences. In the current study, each participant was invited to attend two interviews that incorporated photo elicitation, thereby producing a large set of in-depth data for analysis.

Participants

Women were recruited from a community-based HIV service organisation in Toronto, a large urban city in Ontario, Canada, which provides HIV, sexual health, and support services for South Asian communities (Alliance for South Asian AIDFS Prevention - ASAAP, 2014). English-speaking women who self-identified as South Asian, aged 18 years and older, who had been living in Canada for more than 3 months, were included. Purposive sampling was used (Burmeister & Aitken, 2012; Coyne, 1997; Mason, 2010) to ensure participants possessed similar gender and cultural attributes.

Data Collection

A demographic questionnaire was administered prior to the first interview. Face-to-face semi-structured interviews were conducted with participants. A semi-structured interview guide was developed based on the Episodic Disability Framework, with open-ended questions to explore concepts related to health, illness, the role of culture, HIV stigma, discrimination, and their unique experiences as South Asian women living with HIV in Canada. After the initial interview, participants were asked to return for a second interview to glean additional indepth information. The interview guide for the second interview was developed based on gaps identified in the first round of interviews, including questions about racism and intimate partner violence. During the second interview, a photo/object elicitation technique was used to stimulate dialogue in which participants were asked to bring a picture or object that was 'meaningful' for them to the interview (CohenMiller, 2018; Harper, 2002). This helped in obtaining concrete and detailed information about how personal and social contexts shaped their experiences. All interviews were audio-recorded and transcribed verbatim.

Data Analysis

A thematic analysis approach was used (Vaismoradi, Turunen, & Bondas, 2013) that focused on examining personal strategies and contextual factors that shaped patterns of resilience. Analysis progressed from dwelling on the text to search for meaning, on to interpreting the words, phrases, and sentences, and finally to synthesising ideas to identify key themes related to resilience (Davidson, Paulus, & Jackson, 2016; Sutton & Austin, 2015). Two investigators (SV and PS) independently coded two transcripts of the initial interviews using line by line coding and developed a codebook to describe each code. Using the codebook, they independently coded the remaining transcripts, meeting periodically to reconcile differences. The second set of interview transcripts were reviewed and coded independently by both these investigators, using a similar analytic process. Final categories and themes were developed through consensus of all members of the research team. A qualitative software programme called NVivo11(QSR International, 2017) was used to manage the data and support the analysis.

Ethics

This study received research ethics approval from the Hamilton Integrated Research Ethics Board (Project number: 1789). All the participants provided written informed consent.

RESULTS

Participant Demographics

Eight women participated in the initial interview. Six of them agreed to participate in a second interview (14 interviews in total). All participants were first-generation South Asian immigrant women, who had been living in Canada for an average of 24.2 years (range 6 - 44 years, standard deviation (s.d.) ± 10.2). The mean age of the women was 47.1 years (range 39 - 60 years) and the mean length of time since HIV diagnosis was 15.1 years (range 8 - 25 years). Two women identified as single (25%), three were married (37.5%), one was widowed (12.5%), and two were divorced (25%). Five women (62.5%) lived with a partner or children, and three (37.5%) lived alone. Five women were employed (62.5%), while three (37.5%) were unemployed. Among the eight participants, two had disclosed their HIV status to select family members.

Participants were women of South Asian ethnicity who had immigrated to Canada from India, parts of Africa, South America, the Caribbean, and Southeast Asia. All participants were first generation South Asian immigrants. Two women had come to Canada when they were young (two-and-a-half years old). Seven participants were infected with HIV by their partners or husbands, and one participant was infected through blood transfusion.

Building Resilience

Women coped with and adapted to challenging situations and reconstructed their priorities and reshaped their identities while living with HIV. Resilience is a process of bouncing back from an adverse situation by adopting certain positive living strategies (Fine, 1991). All the women demonstrated one or more resilient qualities. Resilience was developed in several ways. The data analysis resulted in three themes pertaining to strategies used to develop resilience among South Asian women living with HIV, namely: identifying the need for self-care, maintaining social connectivity, and remaining optimistic. These themes are described below with representative quotes.

i. Identifying the Need for Self-care

Women living with HIV identified the need for, and importance of, positive adaptive measures such as self-care, to enhance resilience. Most of the women aspired to maintain good health. While describing their coping strategies, it was evident that they proactively engaged in activities to maintain their health. For example, one woman shared that her routine included:

"Exercising, eating healthy and involving myself in the community and volunteering, working and everything" (Participant 6, age 58, diagnosed with HIV 8 years ago).

Participants' stories highlighted the importance of self-care as a strategy to support resilience. South Asian women often live with strict gender roles and are unable to rest or negotiate their chores in the family; this may contribute to further deterioration in their health and affect their role as caregivers. A woman who was working part-time shared her experience:

"Yeah, because in our culture we housewives have the responsibility to take care of our whole house. In my own life, my husband is positive, and I'm also positive; he doesn't do the housework and I'm the one who has to do (it)" (Participant 2, age 46, diagnosed with HIV 15 years ago).

Despite strict gender norms, women learned to be independent in managing their self-care. Those who did not receive support from their family or the South Asian community, found that self-reliance was the only conceivable way to manage their stress. This sense of confidence contributed to their resilience.

"I'm the only one to pick myself up and bring myself back to reality and nurture myself" (Participant 7, age 46, diagnosed with HIV 16 years ago).

Gender and primary caregiver roles demanded that women perform their everyday chores in spite of health challenges. For some, this contributed to the deterioration of their physical and mental health. A woman who was a single mother and a full-time employee mentioned that due to her health challenges it was difficult to perform her day-to-day activities at home, which eventually affected her parental role.

"And I'm tired. I used to have the energy to do my housework, but now when I come in (home) my body says 'no, you can't'. I like to clean my place on Friday. Like yesterday I didn't do my housework and now my house is a mess. And when you see that also you don't feel comfortable. Where do I start and what do I do? But being a parent there is only so much you can ignore!" (Participant 7, age 46, diagnosed with HIV 16 years ago).

The women incorporated self-management strategies to reduce stress and build resilience. They described their strategies, developed over time, to gain personal control and mastery over their condition. For example, when asked 'who is important in your life?', one woman, who was living alone with her daughter, showed a picture of her pet hamster to emphasise its positive impact on her life.

"I bought that hamster because I am lonely, and I feel that can give me some kind of way I'll get some happiness" (Participant 4, age 44, diagnosed with HIV 8 years ago).

The experience of immigration added another layer of complexity and stress and had a negative impact on the mental health of some women. Though they considered immigration to Canada as a better option for their standard of living, they found it difficult to adapt to the new culture. One woman explained that along with her health challenges, the fast-moving Canadian lifestyle and work system had predisposed her to depression.

"I was diagnosed (with) depression a month ago, maybe that's because of this new place as an immigrant or (maybe because of) health issues. And again, the way I work back home is different. Here I have to (cope with) the Canadian system, all these things have given me too much stress" (Participant 2, age 46, diagnosed with HIV 15 years ago).

Over time the women engaged in strategies to heighten feelings of personal control and mastery over their condition. Many of them stated that living in Canada had taught them to be self-reliant. They had learnt how to seek multiple resources, access information to make informed decisions about their health and expand their social boundaries. One woman showed a picture taken during her Canadian Citizenship ceremony and said:

"Here (in Canada) I learned how to be myself, I have many kinds of knowledge to take care of myself" (Participant 6, age 58, diagnosed with HIV 8 years ago).

Women's stories often portrayed their transformation into confident and autonomous individuals. It was evident that their self-reliance and confidence stemmed from their life experiences.

"I don't let other people lead my life. So, because of that, I see myself even healthier and happier" (Participant 4, age 44, diagnosed with HIV 8 years ago).

The stories revealed that although these women struggled with health challenges, isolation and depression, the support systems available in Canada had shaped their confidence and enabled them to be self-reliant and engage in self-care.

ii. Maintaining Social Connectivity

The participants reported that they often experienced isolation due to their HIV diagnosis. As HIV is a stigmatised disease, it was hard for them to talk about their disease or request support. One woman explained that stigma was one of the reasons for her social isolation:

"In our community, it's very hard to be open, we are being isolated a lot" (Participant 8, age 39, diagnosed with HIV 18 years ago).

After their HIV diagnosis, the women purposefully reconstructed their social supports, such as becoming active members of HIV-related organisations or groups, utilising media to connect with friends, and maintaining close relationships with family. One woman had established various formal and informal support systems, including social media, to boost her resilience.

"I look for people, I read things that people post, even on Facebook. I read something, so I take those things as lessons or signs to me like 'hey chin up, it's going to be okay' " (Participant 1, age 44, diagnosed with HIV 8 years ago).

Women also reported that due to stigma, many HIV positive South Asian women are hesitant to access services from AIDS Service Organisations (ASOs). This is primarily due to the fear of being identified as an HIV positive person by someone in the South Asian community. When asked about HIV stigma, a woman mentioned:

"Yes, Stigma is everywhere, not only in Canada. The stigma is everywhere. That's why people don't come out and tell that they have HIV. Especially the South Asians, they never disclose their HIV status. I know lots of South Asian women who are HIV positive, but they don't even come (to the ASO) here. Because they are afraid if somebody finds out. Stigma is a big thing" (Participant 1, age 44, diagnosed with HIV 8 years ago).

Though women intentionally severed social connections due to HIV stigma or fear of stigma, they purposefully rebuilt connections with individuals whom they trusted. Women mentioned that identifying as a member of an HIV organisation offered them a sense of connectedness. For many, these friendships provided a sense of belonging.

"I have our peers, (and) there are some folks within our community. They are quite sweet. They check in with us (and ask), 'how are you feeling? Why are you working so hard?" (Participant 1, age 44, diagnosed with HIV 8 years ago).

The social supports offered in Canada helped the women to develop resilience. Though they experienced difficulties as immigrants, they acknowledged the benefits of the social networks that were not available in their home countries.

"Here you get help. You have services, organisations. Back home, I don't think you would have any kind of education or any groups. And here there are services to help you out. But in our countries, probably it would be a dark hole" (Participant 8, age 39, diagnosed with HIV 18 years ago).

Women used selective resources to maintain their social connectivity. Those who were employed explained that interacting with others in their work environment was a welcome distraction as it stopped them from thinking about their problems and helped to build their confidence. For a few women, merely maintaining contact with family was beneficial; for others, family members provided concrete

assistance and were their main social support. One woman showed a picture of her family and described the comfort and practical or emotional support she received from her family following her HIV disclosure.

"So at least, when I really need help, my family is there for me. I always get support from my mom" (Participant 4, age 44, diagnosed with HIV 8 years ago).

Women mentioned that after their HIV diagnosis they learnt to rearrange their priorities and identities. Most of them gave priority to their families because it provided a sense of identity and purpose. When asked, "who is most important in your life?", one woman showed a picture of her family and said:

"And the support which I'm getting from them (family), it's so much. I really appreciate. So that's what it is for me, these are so important in my life" (Participant 7, aged 46, diagnosed with HIV 16 years ago).

Women described the positive relationships that they built with their healthcare professionals and said they were comfortable sharing their experiences with them. They developed confidence to make decisions about their healthcare as they believed their healthcare professionals would be non-judgemental and would protect their privacy.

"You're safe in Canada about it (being diagnosed with HIV) and you have all the health care in Canada (for HIV) and support. So, the safety is here in Canada, oh not like back home" (Participant 2, age 46, diagnosed with HIV 15 years ago).

iii. Remaining Optimistic

Racial discrimination was viewed as another potential contributor to mental health challenges, affecting self-esteem and confidence, and predisposing them to depression. One woman, who experienced discrimination at work, described her feelings of depression and isolation:

"I'm struggling at work until now. But, before it (racial discrimination) was hard, I was taking it (racial discrimination) seriously. I even got sick, I was depressed, I was at home" (Participant 7, age 46, diagnosed with HIV 16 years ago).

Inspite of the racism and HIV-stigma that the women faced, being optimistic helped them to build resilience. Although they experienced feelings of isolation and depression, their narratives revealed that they made conscious efforts to

remain hopeful and positive. For some women, religion or spirituality served as a source of emotional support and guidance.

"Yes, I do prayers a lot, that gives me the power to live, it's making me strong" (Participant 3, age 53, diagnosed with HIV 23 years ago).

Women who feared discrimination due to their HIV diagnosis could not receive support from their family or friends. However, they created their own comfort zone. One woman, who was betrayed by her intimate partner and neglected by her family, showed a picture of a painting on her wall, and described how she created a positive and safe environment for herself.

"Oh, this picture is in my house, and it reminds me of being somewhere warm. Whenever I come home from a hard day or whatever, feeling sad or depressed, that I can just look around in my house especially at this photo, and know that I have some kind of warmth or happiness around me" (Participant 8, age 39, diagnosed with HIV 18 years ago).

Most women experienced discrimination based on the colour of their skin, as part of their daily life. One woman described how she experienced racial discrimination while travelling by train or bus:

"For example, if I take the TTC, you know, there might be a Canadian Caucasian. They might look at you, and the way they look at you... If you go somewhere, and you have to do anything, if you need some help, the way they talk to you, they talk down to you" (Participant 8, age 39, diagnosed with HIV 18 years ago).

However, women built their resilience by positive thinking and by setting meaningful goals. They wanted to contribute to communities in a positive way, instead of focusing on their own problems. They developed the ability to cope with their challenges and wanted to accomplish their goals. One woman shared her plans for the future:

"I might pursue a degree in law. I think that's the logical step for me, in terms of understanding some of the legal problems for the people living with HIV" (Participant 1, age 44, diagnosed with HIV 8 years ago).

Most women accepted their HIV status and described moving forward in life, a positive indication of their resilience. One woman said, "HIV is a story, not life", which demonstrated that she was able to maintain a balanced perspective and positive outlook.

Women learned to 'pick themselves up' from challenging situations and positively reconstruct their identities. One woman explained her ability to manage her illness by showing a kaleidoscope during the meaningful object/picture exercise and saying:

"Whenever I was very down, I used to look at this (kaleidoscope). Every time I look at this, it's a different kind of pattern. That's why it is very special. I think it's important to me because it will apply to the overall philosophy in my life. I sometimes think that if we really tried, we could put ourselves in anyone's shoes. That means even with people that otherwise we don't associate with" (Participant 1, age 44, diagnosed with HIV 8 years ago).

Many participants acknowledged their anxiety related to stigma and health. However, these difficult situations often helped them to develop inner strength to navigate challenges and rediscover new meaning in life. One woman narrated how her perceptions about HIV changed over time:

"I take (everything) as a positive thing. I do not take things as a negative thing, even being HIV positive. Being HIV positive made my life different; made my life like thinking about others, not being selfish, being selfless" (Participant 7, age 46, diagnosed with HIV 16 years ago).

DISCUSSION

Results from this study revealed that South Asian women living with HIV in Canada actively used strategies to develop resilience and cope with the challenges they experienced as immigrants and racialized women. Participants described how they adjusted after their HIV diagnosis and resolutely rebuilt their lives in Canada. This ability to selectively address stressors was supported by Perrett and Biley (2013) who claimed that resilience does not develop automatically but is a conscious process involving choice and subsequent action.

Women utilised self-care strategies to nurture their physical and mental well-being. This finding is consistent with Singh, Hays, Chung and Watson (2010) who reported that self-care enabled immigrant South Asian women who experienced childhood sexual abuse to set healthy boundaries and make informed decisions. Furthermore, intentional self-care can heal one's mind, body and spirit (Singh et al., 2010). Ahmad, Rai, Petrovic, Erickson and Stewart (2013) also reinforced those South Asian women who were survivors of intimate partner violence transformed themselves through self-care and involvement at work, which allowed them to move forward in their lives.

The theme of social connectivity attests to the fact that women in this study were aware of the importance of other people in their lives. They valued their families greatly and were worried about the possible lack of family support following disclosure. However, they understood that social support could come in many forms and had rearranged their social connectivity following their HIV diagnosis. Most women were part of a peer group involving South Asian women living with HIV at a community-based organisation; this fostered their resilience through a sense of belonging, support, and compassion from others. Logie, James, Tharao and Loutfy (2011) also found that resilience among women of colour living with HIV was strengthened by building peer supportive HIV-positive networks. Earnshaw et al. (2017) suggested that social support can help in reconstructing and reframing individual thoughts since participants can talk through events in a safe environment. Similarly, immigrant South Asian women who experienced intimate partner violence built their resilience by expanding their social networks and connections with people they trust (Perrett & Biley, 2013).

South Asian women living with HIV who participated in this study were able to maintain a positive outlook on their lives. Similarly, a sense of optimism was identified among women living with HIV in Thailand (Liamputtong & Haritavorn, 2012). The current study also suggests that women's perseverance and willingness to struggle along have reconstructed their lives and identities in a positive way. These findings are consistent with Emlet, Shiu, Kim and Fredriksen-Goldsen (2017) who observed that adults living with HIV who tried to maintain a positive outlook were better able to overcome adversity.

The current study's findings contribute to the under-researched area of resilience among South Asian women living with HIV. Results align with those of Singh (2009) and Zafar (2015) who asserted a need for a resilience framework for ethnic minority women that includes the influence of culture. This is important because the current model of resilience was built on western values which are focused on individualism and individual factors influencing resilience (Zafar, 2015), whereas South Asian culture reinforces collectivism. There is a need to understand relational resilience, as South Asian culture promotes familial social support (Zafar, 2015).

This study has implications for health and social service providers. A growing body of literature suggests that rehabilitation services can reduce disability and improve the quality of life of people living with HIV (Brown, Claffey, & Harding, 2016; Li et al., 2017; Mkandla, Myezwa, & Musenge, 2016; O'Brien et al., 2016). The

current study's findings highlight the importance of ensuring culturally relevant rehabilitation services that address the multi-dimensional nature of disability. For example, one evidence-based HIV rehabilitation approach focuses on increasing physical activity. South Asian women may perceive exercise beyond daily work as a selfish self-care activity (Lawton, Ahmad, Hanna, Douglas, & Hallowell, 2006; Lucas, Murray, & Kinra, 2013); therefore, cultural norms may prevent them from engaging in or joining a sports team or using local leisure facilities for sports or games (Lawton et al., 2006). This reluctance points to the need to explore alternative, culturally relevant approaches to promote physical activity such as Zumba, Tai-chi programmes, dance, or yoga. If these activities are organised through collaborations with community and faith-based organisations, they may provide a more welcoming and culturally appropriate environment (Lawton et al., 2006).

Resilience strategies that can be practiced by individuals living with a chronic illness such as HIV, include negotiating uncertainty and regaining optimism by cognitively reflecting on the past and creating new goals (Perrett & Biley, 2013). Managing HIV also requires engagement in self-care and advocacy (De Santis, Florom-Smith, Vermeesch, Barroso, & DeLeon, 2013). Researchers recommend the utilisation of community-based exercise programmes along with selfmanagement strategies for people living with HIV (Li et al., 2017). In particular, group-based exercise was found to increase social support and adherence to exercise participation, suggesting that exercise programmes may have both physical and psychosocial effects for people living with HIV (Li et al., 2017). Hence, implementing community-based non-traditional rehabilitation, through community service organisations, could provide physical and social support to South Asian women living with HIV. Community-based organisations often offer advocacy and programmes to promote resilience among people living with HIV. It is important that rehabilitation providers understand the social support networks of South Asian women living with HIV in order to facilitate positive connections with peers and promote resilience.

Strengths

The strengths of this study included two interviews with the participating women, as this provided rich data which offered greater scope for analysis. Triangulation of data sources through photo elicitation added further depth to the investigation into the resilience among participants. Photo elicitation technique was an effective

tool to facilitate in-depth understanding and provided scope for discussion of the women's lived experiences. To be specific, the women were hesitant to discuss certain sensitive issues such as racism and intimate partner violence in detail. Photo elicitation technique helped to probe these sensitive topics and convey complex experiences. The study participants presented pictures that they felt were 'important' in their lives and actively engaged in the discussion; this helped the researchers to understand their resilience amidst the adversity they were experiencing. Application of the Episodic Disability Framework (O'Brien et al., 2008) to the lived experience of South Asian women living with HIV strengthened this study as it helped to understand the multidimensional disability experiences of the women.

Limitations

Limitations included the recruitment of participants from only one HIV community organisation in an urban setting, and inclusion of only English-speaking immigrants. Women who do not access HIV organisations, do not live-in urban centres, and do not speak English may be more socially isolated or, alternatively, may be better able to cope with their health challenges. Further research is needed to understand resilience strategies of women who do not use HIV organisations or live in more rural or remote areas.

CONCLUSION

The study findings can be utilised by researchers and healthcare practitioners to understand the resilience of South Asian women living with HIV and other marginalised populations who may share a similar cultural background.

South Asian women living with HIV in this study exhibited resilience, cultivated through strength and perseverance in adjusting to adversity. In spite of the complex challenges they faced, they opened up new pathways to living by building self-care strategies, rearranging their social connectivity, and practicing optimism. Understanding the resilience of racially marginalised women living with HIV through a cultural lens could help to facilitate the development of culturally acceptable self-management strategies.

References

Ahmad, F., Driver, N., McNally, M. J., & Stewart, D. E. (2009). "Why doesn't she seek help for partner abuse?" An exploratory study with South Asian immigrant women. *Social Science and Medicine*, 69(4), 613-622. https://doi.org/10.1016/j.socscimed.2009.06.011. PMid:19576669

Ahmad, F., Rai, N., Petrovic, B., Erickson, P. E., & Stewart, D. E. (2013). Resilience and Resources Among South Asian Immigrant Women as Survivors of Partner Violence. *J Immigrant Minority Health*, 1057-1064. https://doi.org/10.1007/s10903-013-9836-2 PMid: 23616048

ASAAP. (2014). *Alliance for South Asian AIDS Prevention* [Online]. Retrieved February 16, 2016, from https://asaap.ca/

Betancourt, T. S., Meyers-Ohki, S. E., Charrow, A., & Hansen, N. (2013). Annual research review: Mental health and resilience in HIV/AIDS-affected children - A review of the literature and recommendations for future research. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 54(4), 423-444. https://doi.org/10.1111/j.1469-7610.2012.02613.x PMid:22943414 PMCid:PMC3656822

Brown, D., Claffey, A., & Harding, R. (2016). Evaluation of a physiotherapy-led group rehabilitation intervention for adults living with HIV: referrals, adherence and outcomes. *AIDS Care*, 28(12), 1495-1505. https://doi.org/10.1080/09540121.2016.1191611 PMid:27264319

Burmeister, E., & Aitken, L. M. (2012). Sample size: How many is enough? *Australian Critical Care*, 25(4), 271-274. https://doi.org/10.1016/j.aucc.2012.07.002 PMid:22835279

CohenMiller, A. S. (2018). Visual arts as a tool for phenomenology Visual Arts as a Tool for Phenomenology. *Forum: Qualitative Social Research*, 19(1). https://doi.org/10.17169/fqs-19.1.2912

Coyne, I. T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing*, 26(3), 623-630. https://doi.org/10.1046/j.1365-2648.1997.t01-25-00999.x PMid:9378886

Dale, S. K., Cohen, M. H., Kelso, G. A., Cruise, R. C., Weber, K. M., Watson, C., ... Brody, L. R. (2009). Resilience among women with HIV: Impact of silencing the self and socioeconomic factors, *Sex Roles*, 70, 221–231 (2014). https://doi.org/10.1007/s11199-014-0348-x

Davidson, J., Paulus, T., & Jackson, K. (2016). Speculating on the Future of Digital Tools for Qualitative Research. *Qualitative Inquiry*, 22(7), 606-610. https://doi.org/10.1177/1077800415622505

De Santis, J. P., Florom-Smith, A., Vermeesch, A., Barroso, S., & DeLeon, D. A. (2013). Motivation, Management, and Mastery: A Theory of Resilience in the Context of HIV Infection. *Journal of American Psychiatric Nurses Association*, 19(1), 36-46. https://doi.org/10.1177/1078390312474096 PMid:23392433 PMCid:PMC3773721

Earnshaw, V. A., Bogart, L. M., Jumbe, V. C., Ricotta, E., Berthe, S., & Snow, R. W. (2017). A formative study on the exploration of old mosquito nets re-use in fishing communities in five districts in malawi. findings from photos and field observations. *American Psychologist*, 68(4), 225-236. https://doi.org/10.1037/a0032705 PMid:23688090 PMCid:PMC3740715

Emlet, C. A., Shiu, C., Kim, H. J., & Fredriksen-Goldsen, K. (2017). Bouncing Back: Resilience and mastery among hiv positive older gay and bisexual men. *Gerontologist*, *57*(July), S40-S49. https://doi.org/10.1093/geront/gnw171 PMid:28087794 PMCid:PMC5241753

Fine, S. B. (1991). Resilience and Human Adaptability: Who Rises Above Adversity? *The American Journal of Occupational Therapy*, 45(6) 493-503. https://doi.org/10.5014/ajot.45.6.493 PMid: 2063939

Finfgeld-Connett, D., & Johnson, E. D. (2013). Abused South Asian women in westernized countries and their experiences seeking help. *Issues in Mental Health Nursing*, 34(12), 863-873. https://doi.org/10.3109/01612840.2013.833318 PMid:24274242

Haddad, N., Li, J. S., Totten, S., & Mcguire, M. (2018). HIV in Canada - Surveillance Report, *Canada Communicable Disease Report*, 44(12), 324-332. https://doi.org/10.14745/ccdr.v44i12a03 PMid:30906230 PMCid:PMC6390815

Harper, D. (2002). Talking about pictures: a case for photo elicitation. *Visual Studies*,17(1). https://doi.org/10.1080/14725860220137345

Hawa, K. R., Underhill, A., Logie, C., & Loufty, M. (2018). Social contexts and HIV vulnerabilities among South Asian women in the greater Toronto area: Examining social norms. *Health Care for Women International*, 39(2), 129-153. https://doi.org/10.1080/07399332.2 017.1397157 PMid:29095127

Lawton, J., Ahmad, N., Hanna, L., Douglas, M., & Hallowell, N. (2006). "I can't do any serious exercise": Barriers to physical activity amongst people of Pakistani and Indian origin with Type 2 diabetes. *Health Education Research*, 21(1), 43-54. https://doi.org/10.1093/her/cyh042 PMid:15955792

Li, A., McCabe, T., Silverstein, E., Dragan, S., Salbach, N. M., Zobeiry, M., ... O'Brien, K. K. (2017). Community-Based Exercise in the Context of HIV: Factors to Consider when Developing and Implementing Community-Based Exercise Programs for People Living with HIV. *Journal of the International Association of Providers of AIDS Care*, 16(3), 267-275. https://doi.org/10.1177/2325957416686836 PMid:28074681

Liamputtong, P., & Haritavorn, N. (2012). Living Positively: The Experiences of Thai Women Living With HIV / AIDS in Central Thailand. *Qualitative Health Research*, 22(2), 441-451. https://doi.org/10.1177/1049732311421680 PMid:21890710

Logie, C. H., James, L. I., Tharao, W., & Loutfy, M. R. (2011). HIV, gender, race, sexual orientation, and sex work: A qualitative study of intersectional stigma experienced by HIV-positive women in Ontario, Canada. *PLOS Medicine*, 8(11). https://doi.org/10.1371/journal.pmed.1001124 PMid:22131907 PMCid:PMC3222645

Lopez, K. A., & Willis, D. G. (2004). Descriptive versus interpretive phenomenology: their contributions to nursing knowledge. *Qualitative Health Research*, 14(5), 726-735. https://doi.org/10.1177/1049732304263638 PMid:15107174

Lucas, A., Murray, E., & Kinra, S. (2013). Heath Beliefs of UK South Asians Related to Lifestyle Diseases: A Review of Qualitative Literature. *Journal of Obesity*, 2013, 1-13. https://doi.org/10.1155/2013/827674 PMid:23476751 PMCid:PMC3588185

Majumdar, B. (2013). Stigma as a Barrier to HIV Prevention among an Indian-Immigrant Population in Canada: A Qualitative Study. *Primary Health Care*: Open Access, 03 (02). https://doi.org/10.4172/2167-1079.1000137

Mason, M. (2010). Sample Size and Saturation in PhD Studies Using Qualitative Interviews. *Forum: Qualitative Social Research*, 11(3). https://doi.org/10.17169/fqs-11.3.1428.

Mkandla, K., Myezwa, H., & Musenge, E. (2016). The effects of progressive-resisted exercises on muscle strength and health-related quality of life in persons with HIV-related polyneuropathy in Zimbabwe. *AIDS Care*, 28(5). https://doi.org/10.1080/09540121.2015.1125418 PMid:26729347

Morse, J. M. (2000). Determining Sample Size. *Qualitative Health Research*, 10(1), 3-5. https://doi.org/10.1177/104973200129118183 PMid:18174530

O'Brien, K. K., Bayoumi, A. M., Solomon, P., Tang, A., Murzin, K., Carusone, S. C., Davis, A. M. (2016). Evaluating a community-based exercise intervention with adults living with HIV: Protocol for an interrupted time series study. *BMJ Open, 6*(10), 1-12. https://doi.org/10.1136/bmjopen-2016-013618 PMid:18834538 PMCid:PMC2572592

O'Brien, K. K., Bayoumi, A. M., Strike, C., Young, N. L., & Davis, A. M. (2008). Exploring disability from the perspective of adults living with HIV/AIDS: development of a conceptual framework. *Health and Quality of Life Outcomes*, 6(1), 76. https://doi.org/10.1186/1477-7525-6-76

O'Brien, K. K., Davis, A. M., Strike, C., Young, N. L., & Bayoumi, A. M. (2009). Putting episodic disability into context: a qualitative study exploring factors that influence disability experienced by adults living with HIV/AIDS. *Journal of the International AIDS Society*, 2(1), 5. https://doi.org/10.1186/1758-2652-2-5

O'Brien, K. K., Wilkins, A., Zack, E., & Solomon, P. (2010). Scoping the field: identifying key research priorities in HIV and rehabilitation. *AIDS and Behavior*, 14(2), 448-458. https://doi.org/10.1007/s10461-009-9528-z

PMid:19277858

Perrett, S. E., & Biley, F. C. (2013). Negotiating Uncertainty: The Transitional Process of Adapting to Life With HIV. Journal of the Association of Nurses in *AIDS Care*, 24(3), 207-218. https://doi.org/10.1016/j.jana.2012.06.007 PMid:23122905

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Psychological Journal*, 20(1), 7-14. https://doi.org/10.14691/CPPJ.20.1.7

QSR International. (2017). *NVivo* [Qualitative data analysis software]. Doncaster, Victoria, Australia: QSR. Retrieved March 10, 2017, from https://www.gsrinternational.com/nvivo

Singh, A. A. (2009). Helping South Asian Immigrant Women Use Resilience Strategies in Healing from Sexual Abuse: A Call for a Culturally Relevant Model. *Women and Therapy*, 32(4) 361-376. https://doi.org/10.1080/02703140903153229

Singh, A. A., Hays, D. G., Chung, Y. B., & Watson, L. (2010). South Asian immigrant women who have survived child sexual abuse: Resilience and healing. *Violence Against Women*, 16(4), 444-458. https://doi.org/10.1177/1077801210363976 PMid:20224114

Snowden, M. B., Steinman, L. E., Bryant, L. L., Cherrier, M. M., Kurt, J., Leith, K. H., ... Fitzpatrick, A. L. (2017). Dementia and co-occurring chronic conditions: a systematic literature review to identify what is known and where are the gaps in the evidence? *International Journal of Geriatric Psychiatry*, 32(4), 357-371. https://doi.org/10.1002/gps.4652 PMid:28146334 PMCid:PMC5962963

Squires, K. E., Hodder, S. L., Feinberg, J., Bridge, D. A., Abrams, S., Storfer, S. P., & Aberg, J. A. (2011). Health needs of HIV-infected women in the United States: insights from the women living positive survey. *AIDS Patient Care and STDs*, 25(5), 279-285. https://doi.org/10.1089/apc.2010.0228 PMid:21446785 PMCid:PMC3085953

Stucki, G. (2005). ICF linking rules: an update based on lessons learned. *J Rehabil Med*, 37, 212-218. https://doi.org/10.1080/16501970510040263 PMid:16024476

Sutton, J., & Austin, Z. (2015). Qualitative Research: Data Collection, Analysis, and Management. The *Canadian journal of hospital pharmacy*, 68(3), 226-231. https://doi.org/10.4212/cjhp.v68i3.1456 PMid:26157184 PMCid:PMC4485510

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences*, 15, 398-405. https://doi.org/10.1111/nhs.12048 PMid:23480423

Vajravelu, S., O'Brien, K. K., Moll, S., & Solomon, P. (2022). Exploring the disability experiences of South Asian Women living with HIV in Southern Ontario, Canada. *Disability and Rehabilitation*, 1-7. https://doi.org/10.1080/09638288.2022.2037741 PMid:35168465

Vlassoff, C., & Ali, F. (2011). HIV-related stigma among South Asians in Toronto. *Ethnicity & Health*, *16*(1), 25-42. https://doi.org/10.1080/13557858.2010.523456 PMid:21259140

World Health Organization. (2007). *International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY.* World Health Organization. https://apps.who.int/iris/bitstream/handle/10665/43737/9789241547321_eng.pdf

Yang, H. Y., Beymer, M. R., & Suen, S. C. (2019). Chronic Disease Onset Among People Living with HIV and AIDS in a Large Private Insurance Claims Dataset. *Scientific Reports*, *9*(1), 1-8. https://doi.org/10.1038/s41598-019-54969-3. PMid:31811207 PMCid:PMC6897968

Zafar, S. (2015). Familial Abuse of South Asian Immigrant Women: Analysis of the Narratives of Victims. York University. http://hdl.handle.net/10315/30657

Zhou, Y. R., Majumdar, B., & Vattikonda, N. (2016). Culture, but more than culture: an exploratory study of the HIV vulnerability of Indian immigrants in Canada. *Culture, Health and Sexuality*, *18*(9), 1067-1080. https://doi.org/10.1080/13691058.2016.1162328. PMid:27070278