

Disability experiences and resilience strategies of South Asian women living with HIV in Southern Ontario

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Introduction

- In Ontario, there is a steady rise in the HIV incidence among South Asian women.
- The health-related challenges and the disability experienced by this population are under reported.
- **Purpose:** 1. Understand the “lived experience” of disability among South Asian women living with HIV in Ontario, Canada 2. Explore how contextual factors of culture influence the experiences of disability.

Methods

- We utilized interpretive phenomenological methods
- Recruitment was through Alliance for South Asian AIDS prevention (ASAAP) in Toronto, Canada.
- We conducted in-depth semi-structured face-to-face interviews with 8 women with 6 out of 8 women participated in a second interview 9-11 months later.
- We utilized body mapping and photo-elicitation techniques.
- Interviews were audio-recorded and transcribed verbatim and analyzed using a thematic analysis approach.

Participants

 8 women (Mean age of 47.1 years [s.d=5.8]).

 Mean number of years since diagnosis – 15.1 years (s.d=6.7).

Results

Theme	Sub-theme
i) Experiencing Disability	a. Experiencing impairments b. Experiencing challenges to activities and social participation c. Fearing the future or uncertainty
ii) Building Resilience	a. Engaging in self-care b. Maintaining social connectivity c. Remaining optimistic
iii) Experiencing Discrimination	a. Victimizing patriarchal culture b. Shaming and blaming in the family and community c. Fearing isolation and stigma in the community d. Feeling racial discrimination

Representative Quotes

Experiencing Impairments

“My whole body is not normal. When diagnosed with HIV, I was also diagnosed with TB (tuberculosis). And I had another diagnosis, breast cancer.”

Fearing isolation and stigma in the community

“If I disclose, I go to Temple if they know my status, they will never let me into the temple. That I know a hundred percent. Even with friends, I will lose my friends. Come on, no one would want to come near me.”

Shaming and blaming in the community

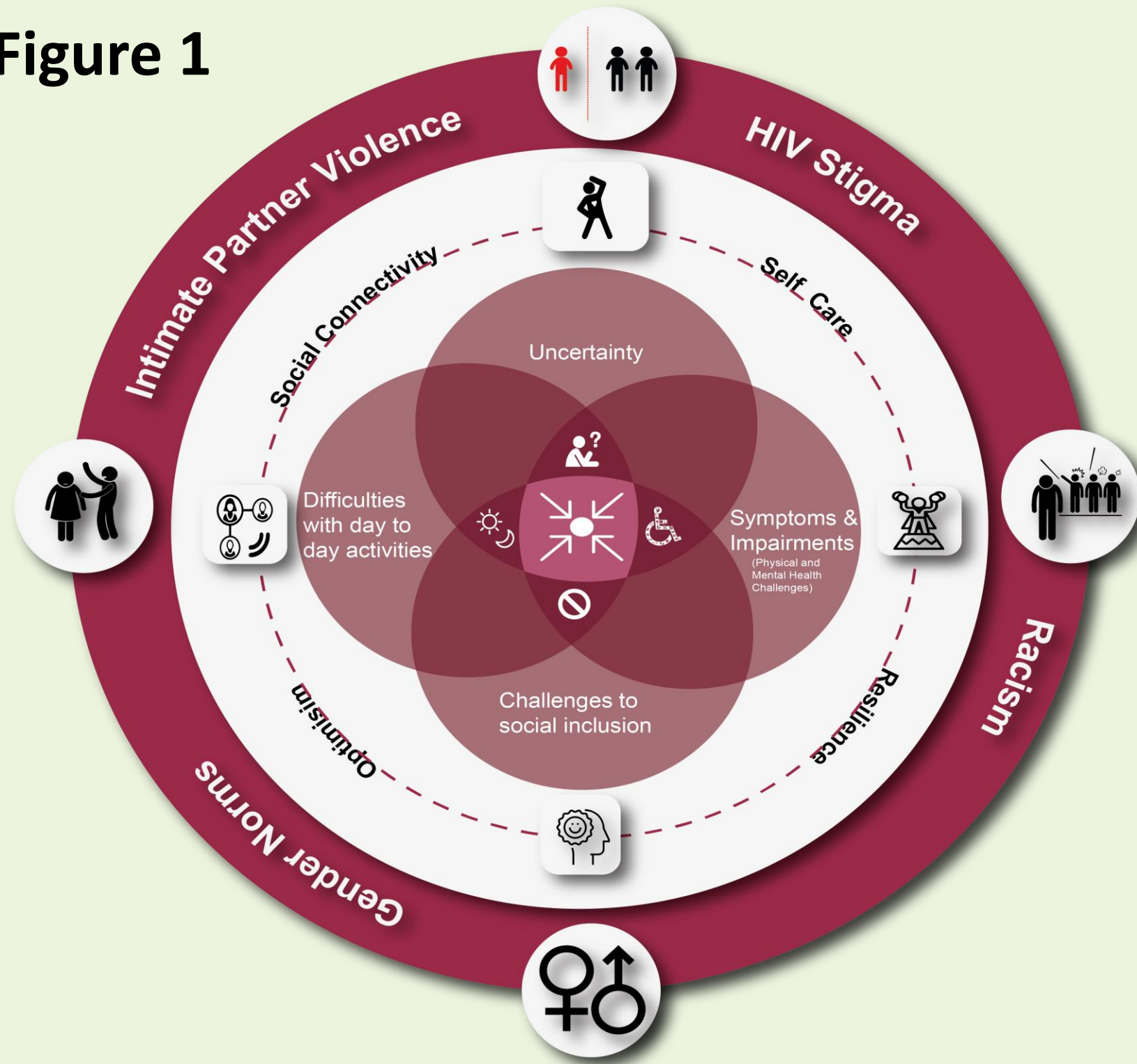
“But for men, even if they talk about that (sex/ HIV diagnosis), it’s not a big deal. They’ll (friends/family) talk for three days and that’s it, over! But, for a women they (friends/family) will never forget. Every time they see your face, instead of seeing you they see HIV.”

Remaining optimistic

“It doesn’t mean that the life stops, and you can't live. I am normal like just any other person.”

Conclusion

Figure 1



Features of Figure 1

1. The dimensions of disability are located within the inner circle, with a center point demonstrating the intersection of the dimensions of disability.
2. Within the outer circle, the contextual factors such as intimate partner violence, gender norms, racism, and HIV stigma are represented.
3. The middle circle represents the resilience developed by the women which act as a buffer between the context and dimensions of disability.

- The complex intersection of illness, gender, ethnicity, and discrimination affected the overall disability experience of South Asian women.
- Despite these challenges, the women manifested resilience by re-constructing their identities, specifically by exhibiting perseverance in the midst of their health challenges, isolation, and patriarchal culture.
- These findings may be utilized by researchers, program planners or health care practitioners to understand the disability experiences of South Asian women living with HIV or other marginalized population who may share a similar cultural background.