



Challenges to Social Participation in Older Women Living with HIV

Patricia Solomon,
Jennifer Siemon, Lisa Blenkhorn,
Kelly O'Brien, Seanne Wilkins,
Nicole Gervais



Background

- In addition to physical sequelae of HIV infection & treatment PHAs face challenges to social participation as they age
- Social participation is an indicator of wellbeing and a key determinant of successful aging
- Influenced by presence of social networks, a sense of belonging and relationships

Gender Influences on Social Participation

- Social roles
- Poverty, depression, isolation and fear of disclosure and stigma contributes to social isolation
- Children, having “balance”, and access social networks enhances social participation

Need to Examine Social Participation in Older Women

- Few studies on older women
- Greater need for support groups and more specific knowledge (Emlet, 2011)
- Ageism (Scrimshaw and Siegal, 2003)
- Older women constitute a growing proportion of PHAs in Canada

Goal

To describe factors and strategies influencing social participations in older women living with HIV.

To develop a theoretical model of social participation in older women living with HIV.



Methods

- Qualitative study
- Women recruited through ASO and clinics
- Eligibility: 50 years or older, oral communication in English



Methods

- Semi-structured interviews exploring:
 - self-care & household management
 - relationships with others
 - work
 - access to health care
 - social services support



Analysis

- Grounded theory approach- open coding technique
- 3 transcripts coded independently
- Coding scheme established
- Remaining transcripts coded independently
- Themes developed which informed development of conceptual model

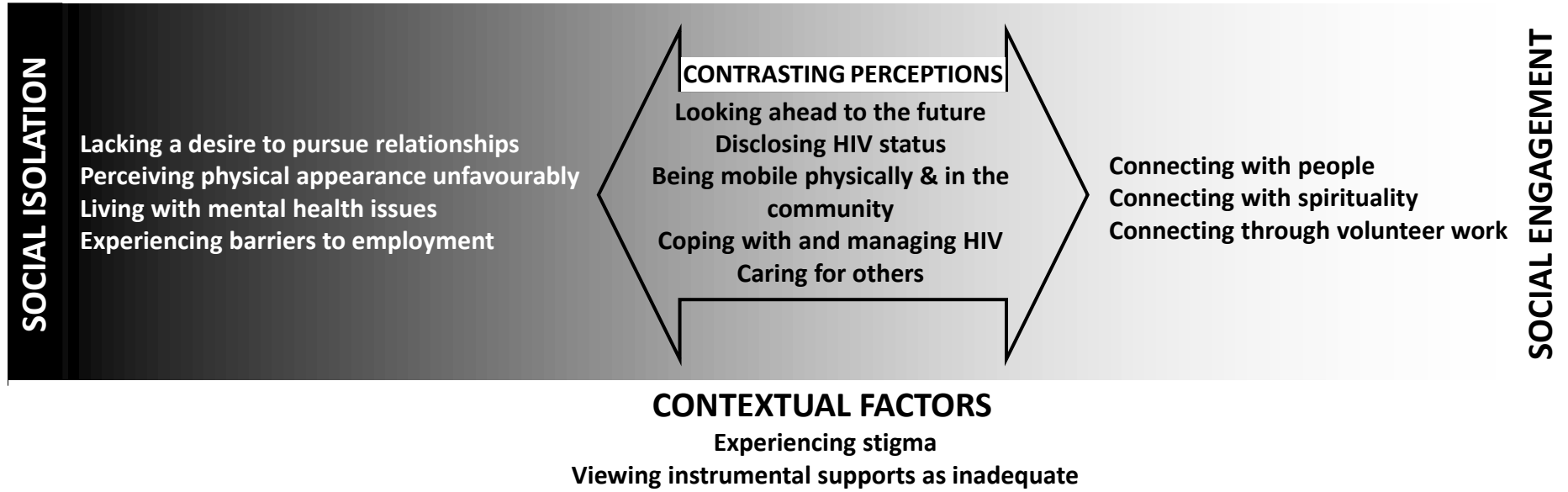


Results

- 20 women including 1 MTF transgendered
- Mean age = 55 years
- Mean length of diagnosis = 12.6 years



Model of Social Participation in Older Women Living with HIV





Looking Ahead to the Future

- “I don’t plan on having any disease beat me. I want to beat the disease. I wanna die of something natural like old age”
- “To look into the future is kinda scary for me... what do I have to look forward to now? What is it that I want to do?”

Disclosing HIV Status

- “In my life there are two groups of people. There are people that are aware of my status... so I discuss stuff with them and they’re usually long-term friends... Then there are people that don’t know my status and I don’t discuss anything about HIV with them”

Being mobile physically & in the community

- “the only thing that holds me back is I no longer have a car... when you’ve had your freedom, you own everything, and then you’re dependent on others... That has been a challenge”



Coping with and managing HIV

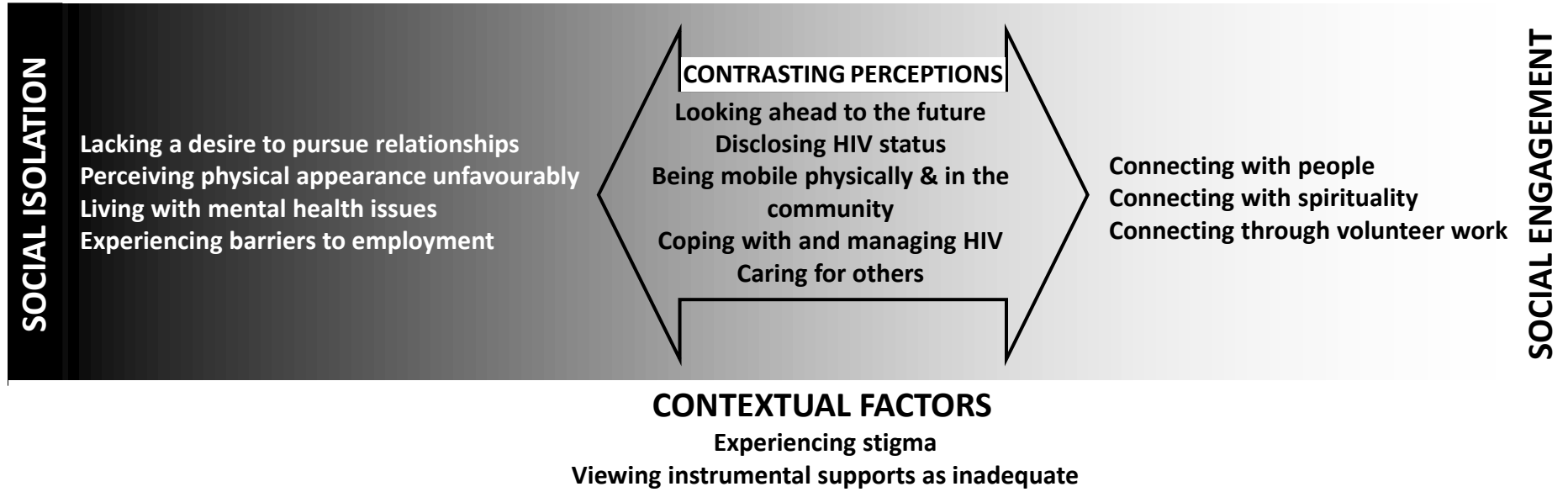
- “The aging with HIV at this point is pretty good compared to everything else. You know... it’s not bothering me at all”
- “I feel like, you know, I have spent a lot of time involved with health services... certainly more than I would [like]”

Caring for others

- “I think women have too many things to worry about, especially if we are women and a mother at the same time. You are always not first... in many things, you know? You put someone first if you have a child like me, so you’re mom, you put the child first”



Model of Social Participation in Older Women Living with HIV





Experiencing age related stigma

- “I don’t look like an HIV-positive person, you know, I’m too old, too grey, whatever. I don’t fit into anybody’s idea of what it is”



Viewing instrumental supports as inadequate

- ... “The only area where I’m feeling totally discriminated against is housing”
- “We have to fight. And we fight and we fight and we fight to get [support payments]”

Implications

- First to show social participation on a continuum with contrasting perceptions variably influencing participation
- Highlights important role of environment
- Some challenges are not unique to older women



Implications

- Some older adults grow more resilient and adaptable as they age
- Need to consider the supports we provide to encourage movement to the right side of continuum
- Need for widespread interventions to combat multi-layered stigma



Thank you

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 - AIDS Niagara