

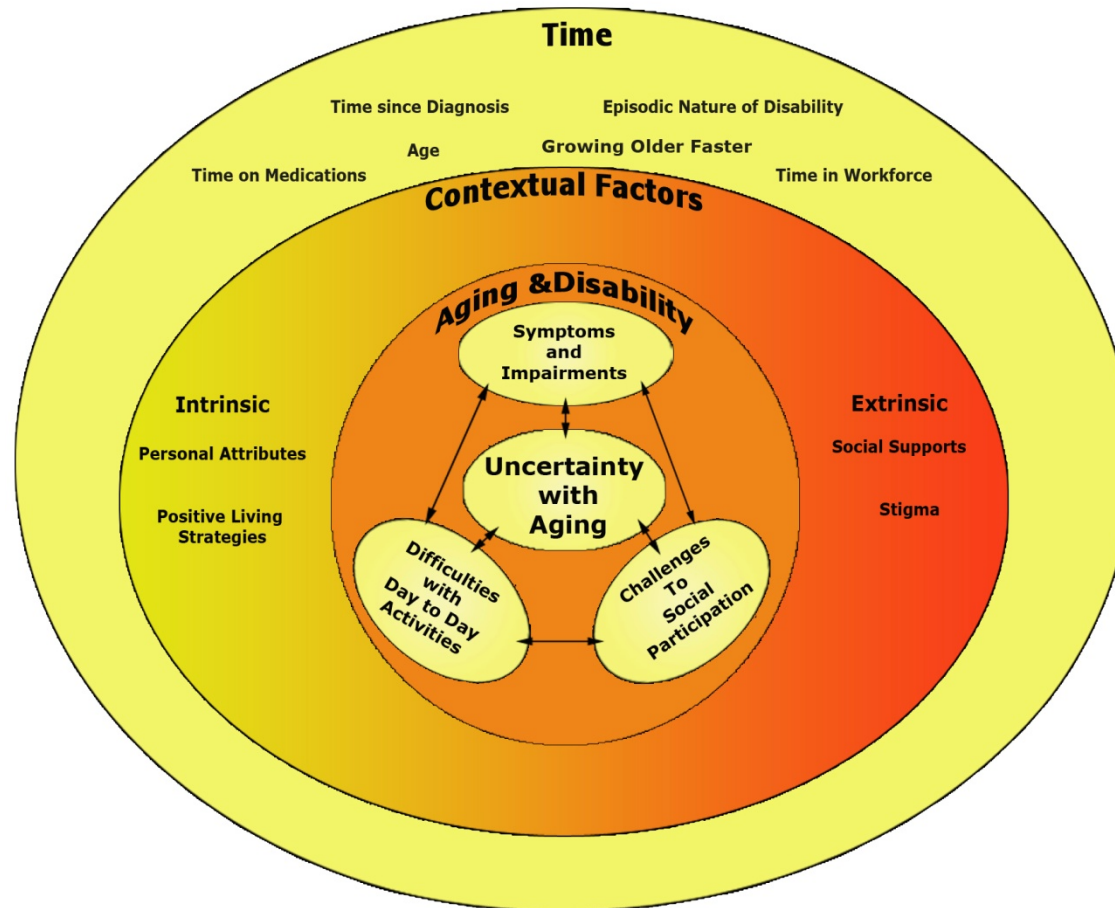


A Qualitative Longitudinal Study of Episodic Disability Experiences of Older Women Living with HIV

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A model of disability experienced by adults aging with HIV

Solomon et al, 2014



Purpose

To examine the disability and associated uncertainty experienced by older women living with HIV *over time*.

Study Procedures

- Longitudinal qualitative study
- Semi-structured interviews based on ICF and EDF
- 10 women > 50 years recruited through ASOs
- Each participant interview 4 times over 1 ½ years

Longitudinal Qualitative Analyses

- 2 directions: cross-sectionally and longitudinally
- Cross-sectionally: participant profiles and group profiles *after each round*
- Longitudinally: comparison of data for same participant AND comparison of group profiles over time

Participants

- 10 women 51-61 years (median=54)
- Median time since diagnosis = 12.5 years
- 5 women on disability, 3 working, 2 seeking employment
- 2 identified as visible minorities, 1 indigenous Canadian
- All women completed 4 interviews

Two Themes

- 1) Living with multiple and complex sources of uncertainty
- 2) Dealing with uncertainty over time

Living with Multiple & Complex Sources of Uncertainty

Unpredictable
Health
Challenges

Worrying
About
Cognition

Unreliable
Weather

Fearing Stigma
& the Effects of
Disclosure

Maintaining
Housing &
Adequate Finances

Fulfilling
Gendered &
Family Roles

Unpredictable health challenges

“ I can't tell a good day from a bad day when I wake up. It's just when I get someplace and it just becomes bad.” (P6)

Worrying about cognition

“ Take your meds. Yeah, I have forgotten....I still forget what I’m going to do. I know a lot of people who ... you attention....I got to go get something or whatever and by the time you get there I stand there and try and figure out what I am here for.” (P9)

Unreliable weather

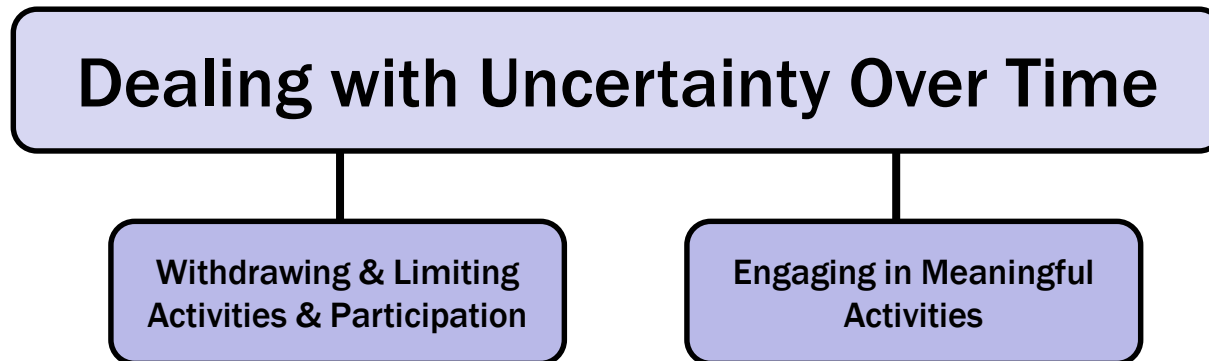
“ There’s not very much to do in the winter. I don’t really go out much, so I just hate it.”
(P8)

Fearing stigma and disclosure

“I applied for a job here and I didn’t get the job and somebody else has been in that job. Somebody else who is a lot less qualified both educationally and experientially, but, you know he’s a gay man.” (P2)

Fulfilling gendered and family roles

“I was having problems with being a grandmother and not being the grandma that I wanted to be, you know, doing a good job and the responsibility of being a grandmother.” (P9)



Withdrawing and limiting activities and participation

- Limited disclosure
- Fears of getting ill
- Reluctant to burden families/friends
- Winter weather
- Increased social isolation

Engaging in meaningful participation

- Women who thrived over time
- Positive outlook
- Sense of purpose
- Lifestyle change



“I’ve learned I have resilience.” (P3)

So What?

- Reinforces our model in which unexpected fluctuations in illness and health result in uncertainty and worrying about the future
- By following over time complexities of managing multiple health challenges highlighted

Effects of stress

- Women experienced high levels of uncertainty and stress
- Stress may accelerate cognitive aging in PLWH (Vance et al, 2016)
- Association between anxiety and mild cognitive impairment in general population (Lenze and Butters, 2016)
- Multimodal integrative approach to management of anxiety

Environmental influences

- Uncertainty of weather affected mobility and social participation
- Weather is a risk factor for social isolation and well being
- People aging with HIV are at increased risk for social isolation

Stigma

- Multi-stigma adds to uncertainty
- Unwillingness to disclose can lead to increased social isolation
- Need to learn to navigate self-stigma

Reinforcing Rehabilitation Approach

- Interprofessional
- Client centered management of disability
- Self-management approaches to deal with uncertainty

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