



“I’ll Bop till I Drop”: Preliminary Findings from a Longitudinal Study on Aging with HIV

P. Solomon, K.O’Brien, S. Nixon,
L. Letts, L. Baxter, N.Gervais

Background

- Growing older an episodic illness leads to many uncertainties that contribute to disability
- Most studies on age related challenges with HIV are cross-sectional
- Aging and episodic disability is a temporal process best understood in longitudinal study designs

Why is it important to understand episodic disability?

- Understand the *consequences* of co-morbidities & how these change over time
- Chronological age often less relevant in explaining disability than environment
- Understand the challenges over time and the strategies participants use

Study Purpose

To understand the experiences of aging with HIV over time through a disability and rehabilitation lens

How does the episodic nature of HIV and the associated uncertainty shape the disability experience of adults aging with HIV over time?

How do participants define successful aging?

Methods

- Qualitative longitudinal cohort
- Study design allow us to understand how and why changes occur
- Same participants interviewed on 4 occasions over 1.5 years
- Interview guide based on the Episodic Disability Framework

Methods

- Recruited from ASOs in Hamilton, Toronto, Niagara and London, ON
- Men and women > 50 years
- Honorarium after each interview and completion of study
- Interviews audiorecorded and transcribed

Analysis

- All team members contributed to developing a coding
- We developed cross-sectional profiles of each participant for each interview
- Longitudinal analyses involved comparison of data of same participant over time
- Content analysis of perceptions of successful aging

Results

- 24 participants interviewed on all 4 occasions for 96 interviews in total
- 14 men and 10 women

Demographics

- Mean age of 57.5 years (range 50-73)
- Mean time since diagnosis of 18.4 years (range 6-30)
- Reported as single – 64% men, 30% women
- Working – 35% men, 30% women

Common Episodic Symptoms

- Pain 79.2%
- Fatigue 79.2%
- Sleep disturbances 62.5%
- GI issues 37.5%
- Arthritis 33.3%
- Neuropathy 25%

Common Episodic Cognitive Symptoms

- Memory challenges 79.2%
- Depression/negative thoughts 70.8%
- Stress/anxiety 45.8%
- Difficulty focussing 41.7%

Episodic Activity Levels

- Walking - important form of exercise and enabler of socialization
- Impacted by weather, pain, GI issues, fear of falling

Episodic Activity Levels

- Exercise – participants recognized the importance of exercise beyond walking
- Motivation and maintaining a program was hard to maintain in the face of “bad days”

Episodic Social Participation

Work and volunteer activities were very episodic in nature

- precarious nature of employment
- impacts on social engagement & support

Uncertainty

- Many sources of uncertainty
- Some identified in the past – ex: long term housing availability, source of symptoms
- New uncertainty – weather, caregiver burden and worries about dementia

Components of Successful Aging

- Acceptance
 - “coming to terms with the realities of aging”
- Need to be positive
 - “ Appreciate where you are and what you can do and adjust to that.”

Components of Successful Aging

- Maintaining social support and connectedness
- Healthy lifestyle
- Engaging in meaningful activities

Components of successful aging

- Taking responsibility

“(there could be) a long stretch of time where there’s no episodes. And it could be incredible fatigue, nausea for no apparent reason. And sometimes you have to do a problem solving thing where, is it something I’m eating? Is it causing nausea? Or is it the meds? You got to do like Sherlock Holmes. So a lot of times you deal with it yourself and if you can’t solve it that’s when you go for professional help.”

Agreement between judgement & beliefs of successful aging n=24

	Seem to be aging successfully	Seems to NOT be aging successfully	Total
Believes themselves to be aging successfully	12	6	18
Believes themselves to NOT be aging successfully	2	4	6
Total	14	10	24

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Summary

- Findings confirmed the episodic nature of symptoms, day to day activities and social participation
- Congruence between “general” literature on successful aging and participants’ perceptions
- People believe they are aging well in spite of significant adversity

Implications for Rehabilitation

- Need to help PLWH understand triggers of episodes and how to cope with “bad days
- Emphasis self-management strategies, promoting confidence and self-efficacy
- Understand individual’s definitions of successful aging and their goals

Next steps

- Examine the positive living strategies of “successful agers”
- Gender analysis → women participants fared more poorly
- Examine how uncertainty shapes disability over time
- Examine contextual factors that influence disability over time

Acknowledgements

- Funding for this project was provided through the Canadian Institutes of Health Research
- Thanks to Toronto People with AIDS Foundation, Hamilton AIDS Network, Positive Living Niagara, Regional HIV/AIDS Connection
- Thanks to the men and women who generously gave of their time.