



## Uncertainty, Aging and HIV

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## Research Team

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## Uncertainty

- High levels associated with difficulty coping, lower Q of L, depression in other chronic diseases
- In HIV stigma & social isolation exacerbate uncertainty (Brashers et al, 2003)
- Influence of episodic disability



## Purpose

To describe the contribution of uncertainty to the disability experienced by older adults living with HIV.

## Context

- Large qualitative study to develop a theoretical model that describes disability experienced by older adults living with HIV
- Men and women living with HIV and over the age of 50 years
- Recruited from ASOs and clinical sites in Toronto, Hamilton and Southern Ontario



## Methods

- In-depth interviews using the ICF and EDF as a basis
- Audiotaped and transcribed verbatim
- Grounded theory analysis by team
- Validity check focus groups

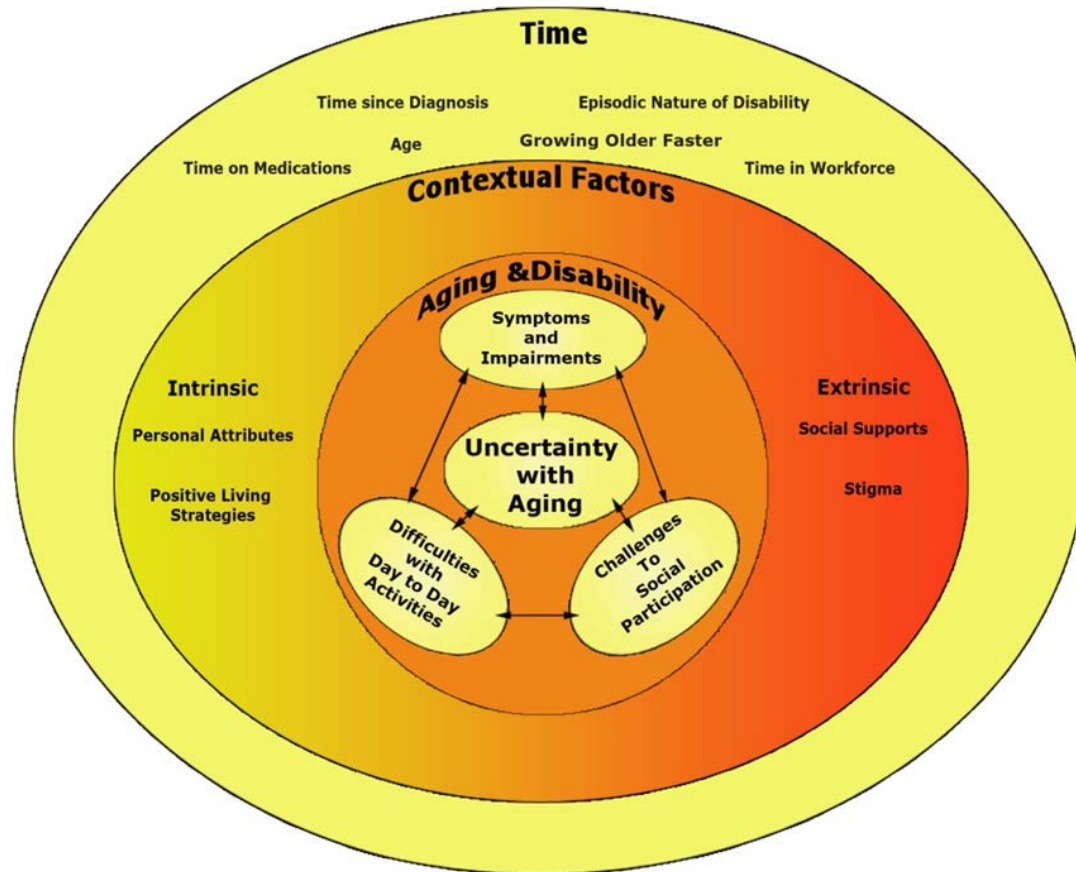


## Demographics of Participants

	Males (n=29)	Females(n=20)	Total (n=49)
Median Age (range)	55 years (50-74)	53.5 years (50-69)	54 years (50-74)
Median # of Years since Diagnosis (range)	14.0 years (1 yr – 26 yrs)	12.6 years (6 mths -24 yrs)	13.5 years (6 mths-26 yrs)
Working full-time (%)	1 (3%)	2 (10%)	3 (6%)
Working part-time (%)	7 (24%)	3 (15%)	10(20%)
Volunteering (%)	11 (38%)	2(10%)	13(27%)
Retired or not looking for work (%)	10 (34%)	8 (40%)	18 (37%)



## Our model

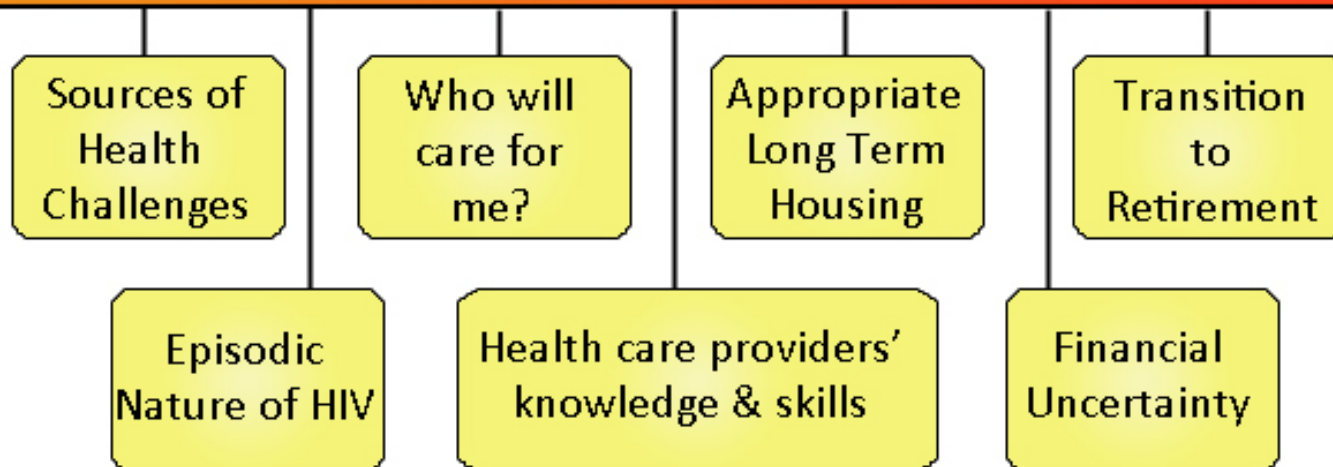






## Uncertainty

### Uncertainty related to Aging with HIV





## Source of health challenges

Well, as I said is it AIDS or is it age? I mean this morning when I was getting up off ... my bed is low and, I wasn't that sure footed. Is it age or is it AIDS?"

## Health provider knowledge & skill

If I went to a doctor and said: 'Well, I've been living twenty something years with HIV, I'm fifty. What's my prognosis for the next twenty something years?' [He will say] 'I don't know.' Because it's true, he doesn't know. He can't tell me 'Well, as a person who's been living with the disease for so long, ... cancers can accelerate. Cardiovascular disease can accelerate. Your bone density can decrease rapidly because of HIV.... The long term side effects of you taking this medication can have these effects with your aging and HIV.' They can't tell me that.

## Financial uncertainty

But economically [growing older] is a bit scary because in.... in a certain sense ..., I haven't put away [any money] and I haven't been able to put away. You know, [there are] choices you make and then the realities that affect those choices as well.

## Transition to Retirement

Sure I feel left out when a lot of people are retiring. I brush it off, I just jokingly say “will I be working until I’m 80?” and my boss says “you think you’ll be climbing up those stairs for that much longer?”. And I say “Hey I don’t have a choice” - so I’ll figure it out when I get there.

## Appropriate long term housing

It's big... Housing is everything. Because we are going to get sicker. Dementia's going to come even as old age as well as HIV. And where are we going to be? You know, are nursing homes ready for that? I don't think so. I don't think nursing homes are ready for even a gay senior to come in [to a long-term care facility].



## Who will care for me?

I think about relying on other people, you know, like there's only one person who's going to be the best server. For me, it's got to be me. If I have to rely on other people I'm not going to get the level of service ... that I've become accustomed to, right?

## Episodic nature of HIV

[If you] cancel 3 or 4 times on people and they get very grieved about it 'cause it's just going to be an ongoing thing. So, if you don't stay involved with certain friends then you get left by the wayside.





## Implications

- With new research emerging no one health professional can have all the knowledge
- Emphasizes need for interprofessional approaches to care



## Implications

- Social isolation is a general risk factor in aging
- Older adults with HIV at increased risk for social isolation & depression (Shippy & Karpiac , 2005; Emlet, 2006)
- Programs & policies to promote social interaction and support are essential



## Implications

- Financial & retirement uncertainty highlight need for retirement benefit reform
- Policies which promote flexibility are needed



## Implications

- Stigma leads to housing barriers related to age, HIV and sexual preference (Furlotte et al, 2012)
- Ageism can exacerbate HIV related stigma (Brennan, Emlet and Eady, 2011)
- Points to importance of ongoing education and anti-stigma campaigns & ongoing need to assess impact of stigma

## Why is this important?

- Uncertainty appraised as dangerous will be perceived as a threat and contribute to further disability
- Need to understand how to support PHAs
- Rehabilitation provides a bridge between biomedical and gerontological approaches that support successful aging

## Acknowledgements

This research was supported by a grant from the Canadian Institutes of Health Research.

We greatly appreciate the time and commitment of all the participants in this research.