

# Aging with HIV: A Model of Disability

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HIV and Aging

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**CHANGING THE COURSE** OF THE  
**HIV PREVENTION, ENGAGEMENT** AND  
**TREATMENT CASCADE**

# Aging & HIV

- People with HIV now survive for 30-50 years after infection, and an increasing percentage of people living with HIV (PHAs) are over the age of 50.
- These people have to cope with the health challenges of the virus, the side-effects of cART, and the decline that comes with getting older.
- From a rehabilitation perspective, these challenges are referred to as disabilities

# Disability and Rehab

- Focussed broadly on promoting quality of life and dealing with physical, emotional, social and professional challenges
- Learning to live with illness and resulting disability
- Looking beyond simple medical management to quality of life, and interventions that will help the client remain engaged with their community.

# Purpose

- To understand the health related challenges, or disabilities, that span physical, cognitive, emotional and social life domains.
- To develop a model that described these disabilities experienced by those aging with HIV.

# Methods

- Semi-structured interviews with HIV positive adults 50 years or older.
- Recruitment through HIV clinics and AIDS service organizations (ASOs) in Southern Ontario.
- Interview questions explored various aspects of social participation: self-care and household management; relationships with family, friends and partners; employment; and access to health and social support services.
- The data were analyzed using a constructivist grounded theory approach to develop codes and categories.
- The relationships among categories was determined and informed the development of the preliminary model.

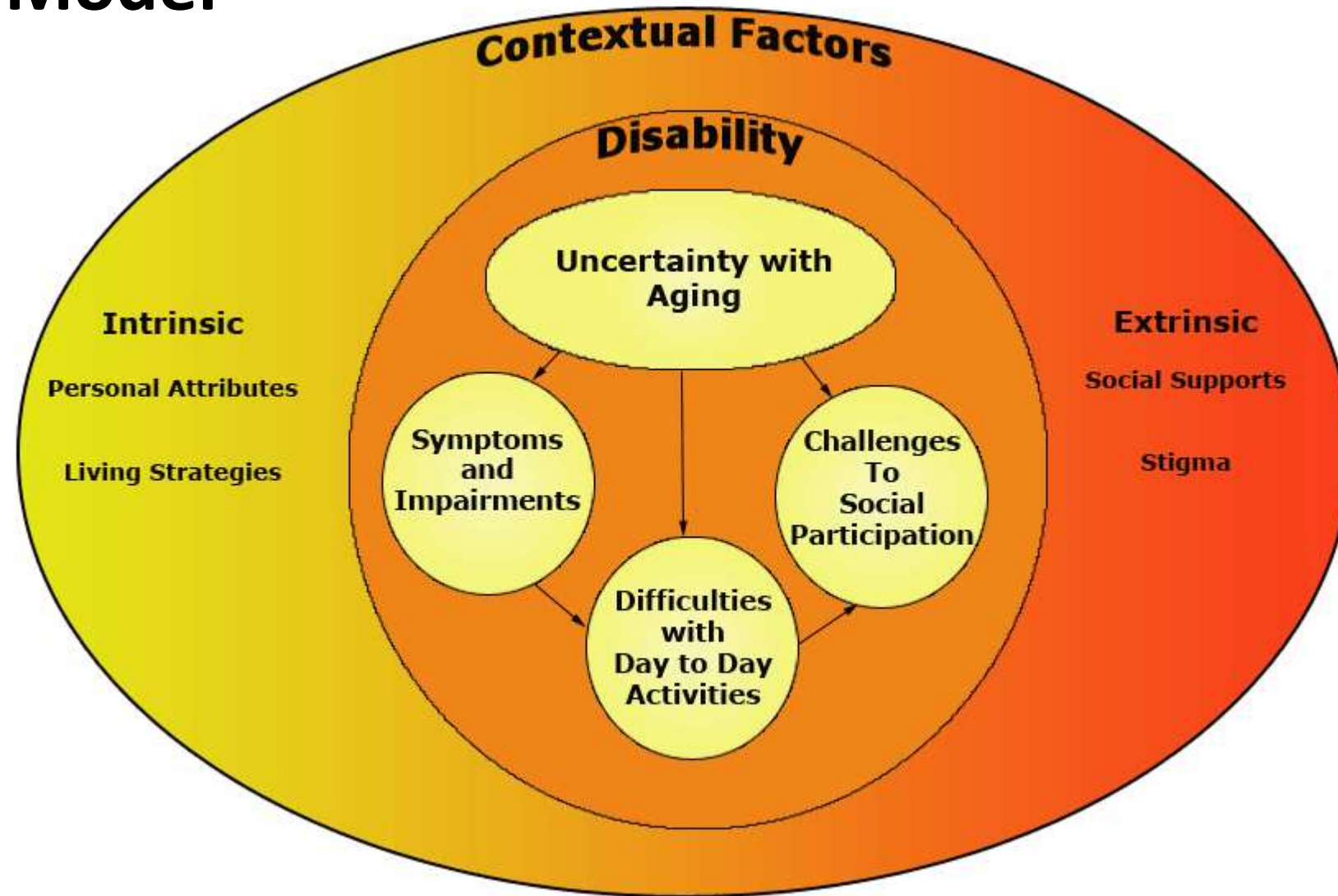
# Results

## Participants

	Males (n=29)	Females (n=20)	Total (n=49)
<b>Median age (range)</b>	55 years (50-74)	53.5 years (50-69)	54 years (50-74)
<b>Median # of Years since Diagnosis</b>	14.0 years (1-26)	12.6 years (.5-24)	13.5 years (.5-26)
<b>On anti-retroviral therapy (%)</b>	17/18 (94%) – 11 missing responses	17/18 (94%) – 2 missing responses	34/36 (94%)

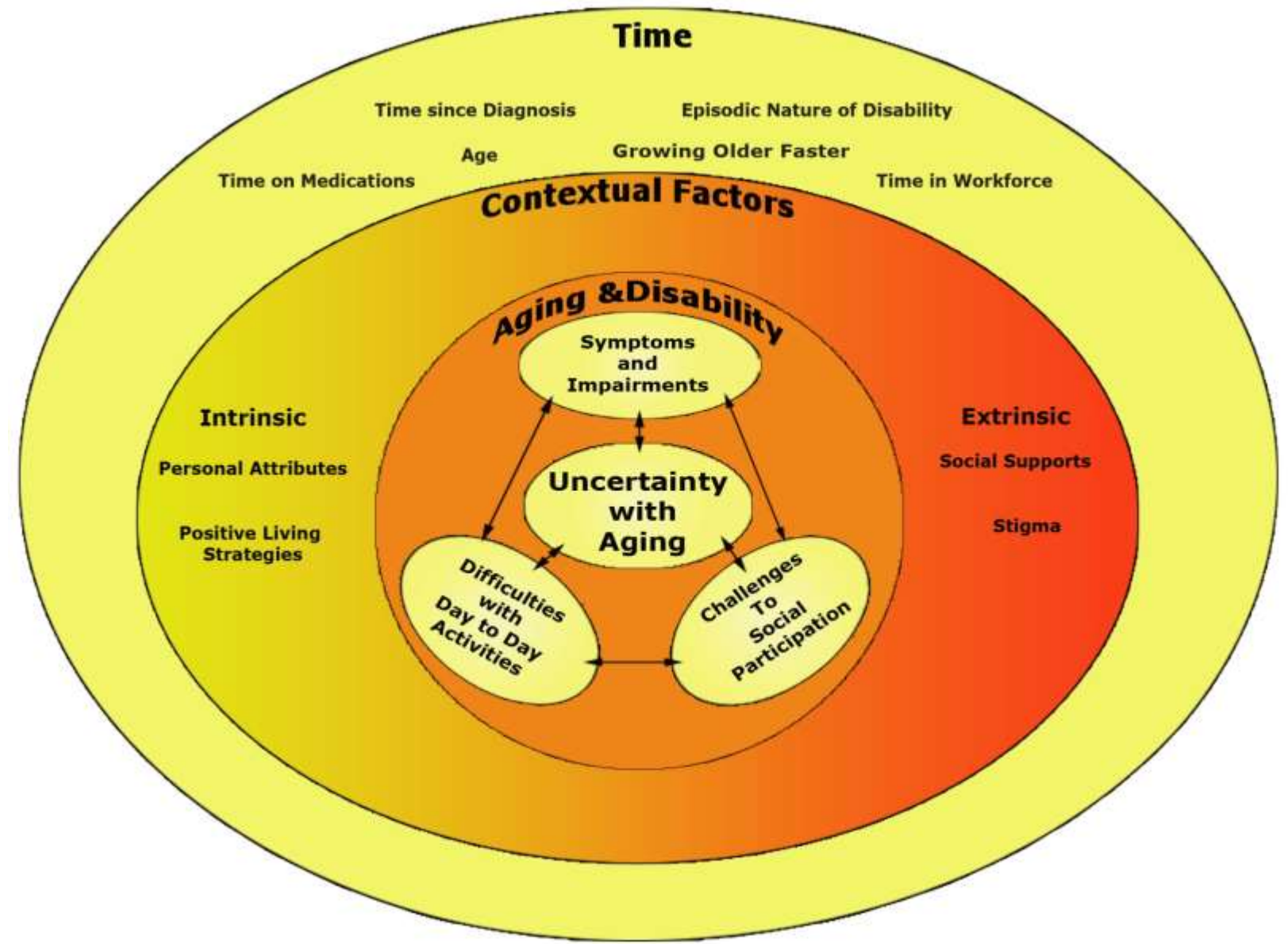
# Results

## Preliminary Model



# Validity Check

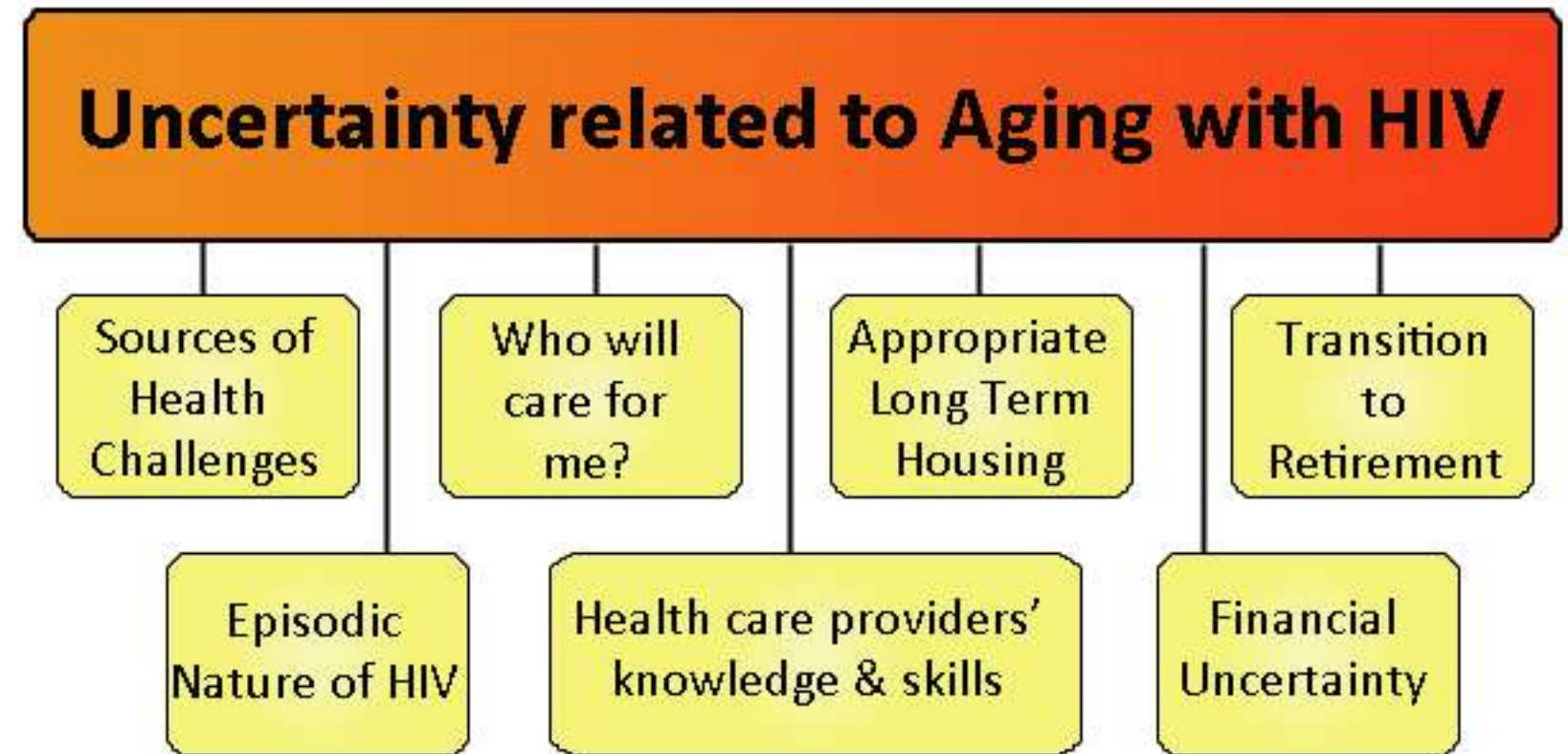
- Validity check focus groups provided feedback on the preliminary model and influenced revisions to result in the final model of disability.
- 17 participants (13 men and 4 women) took part in the validity check focus groups.





# Disability

- Uncertainty
- Symptoms and Impairments
- Difficulties with Day to Day Activities
- Challenges to Social Participation



# Intrinsic Contextual Factors

## Personal Attributes

*(Fixed)*

- Age
- Gender
- Ethnic Background
- Other Health Conditions

## Positive Living Strategies

*(Modifiable)*

- Selective social interactions
- Keeping a positive attitude
- Maintaining a Sense of Control
- Focusing on other aspects of life

*And I went to see my doctor today, and he says, “It’s time to think about you” because you get into this too much and there’s so many people who need some help, that you forget about yourself. And it’s time for me to do so. And I’m planning to do that.*

# Extrinsic Contextual Factors

- Social support from family
- Social support from friends
- Social support from organizations
- Stigma

## ***Social Support***

*“(the support of friends) has given me a new lease on life, I can get back to doing what we would normally do when we were younger.”*

## ***Stigma***

*“I don’t tell anybody. I’m sure if I tell my group members, their behaviour would totally change towards me. So that’s the reason I don’t tell anyone.”*

# Time

- *“I think for us older ones, [time’s] made things worse, because we were all ready to go like everybody else we saw dropping around us, and then all of a sudden, well, we’re still here, so we went through the survivor’s guilt thing, ‘well, why are we still here and why are they not still here?’ and now we’re at the ‘oh gosh, we’re getting old. Why are we getting all these old people diseases too?’ Sort of a double whammy.”*



# Why is this important?

- The model helps us to identify those factors that are modifiable to prevent or reduce disability.
- Uncertainty was identified as the core of disability with this population and suggests the need for interventions to address these causes of uncertainty.
- Unique to this population is the element of time, which surrounds and influences all aspects of disability. This indicates the need to study aging among PHAs from a longitudinal viewpoint.
- It reinforces the need for interventions to reduce stigma, including age related stigma.

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