



Aging with HIV: Uncertainty, Disability and Time

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“Oh gosh – we’re getting old. Why are we getting all these old people diseases too? Sort of a double whammy.”

“I’m amazed I am aging with HIV. That 19 years is a lifetime. That’s a long time. I feel privileged. I feel there’s too many that have gone too early. And so I think that it’s a positive experience. I’m going to keep growing older.”

Who needs models and frameworks??

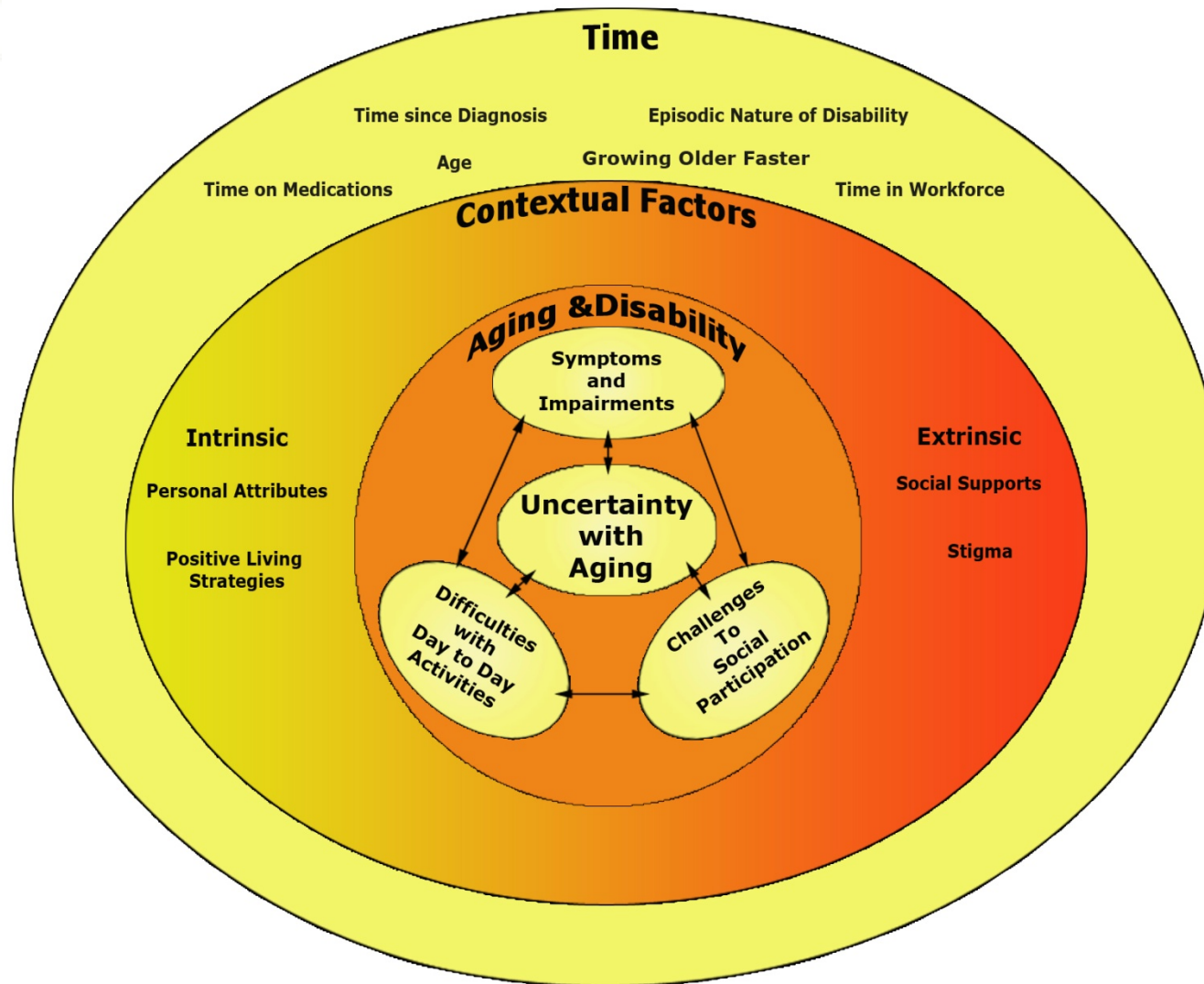
- Helps develop a plan of action for research
- Informs clinical practice when evidence is still emerging
- Often raises more questions than answers!

Understanding Aging with HIV

- Used a disability lens (ICF) and the episodic disability framework
- What disabilities are adults living with HIV experiencing as they grow older?
- Does the episodic nature of HIV influence their experiences?
- What personal and environmental factors are important?

What did we do?

- Interviewed 29 men and 20 women over 50 years
- Explored social participation, self-care, household management, relationships and social support, employment, access to health and social services
- Qualitative analyses and development of the model
- Validity check focus groups



Uncertainty

Uncertainty related to Aging with HIV

Sources of
Health
Challenges

Episodic
Nature of HIV

Who will
care for
me?

Health care providers'
knowledge & skills

Appropriate
Long Term
Housing

Transition
to
Retirement

Financial
Uncertainty

Source of health challenge

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?"

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].

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, choices you make and then the realities that affect those choices as well.

Builds on the EDF

- Health & social service providers have a role to play in supporting coping with uncertainty
- Element of time that influences the entire disability experience
- Complex relationship that needs more inquiry

More Questions

What can we learn about successful aging from gerontology?

How do we promote the positive concept of resilience and self-management strategies?

How do we promote coping with uncertainty?

One last point.....

Aging and episodic disability are temporal processes which can only be understood through longitudinal study.

So.....

Longitudinal Study

- Recruiting 24 men and women over the age of 50
- 4 interviews over 16 months (96 interviews!)

Next steps

- What age related changes in disability, and health occur over time and how do these occur?
- How does uncertainty shape the disability experience of adults aging with HIV over time?
- What are the perceived contextual factors (intrinsic and extrinsic) that influence the experiences of disability over time in older adults living with HIV?
- What factors contribute to perceptions of successful aging over time?
- How do the gender related disablement experiences of men and women aging with HIV differ over time?
- What rehabilitation strategies and supports are required by older adults with HIV over time?

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