

Aging with HIV and Disability: The Role of Uncertainty

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Aging with HIV and Disability: The Role of Uncertainty

Abstract

Due to advances in treatment people with HIV are living longer and developing disabilities related to the virus, adverse side effects of medications and aging. Illness related uncertainty has been shown to contribute to disablement, however, there is little understanding of the uncertainties related to aging with HIV. The purpose of this research was to understand the contribution of uncertainty to the disability experienced by older adults living with HIV. Forty nine men and women living with HIV and over the age of 50 years participated in in-depth qualitative interviews exploring various aspects of social participation and disability. Transcriptions of the interviews were analyzed using a grounded theory approach. Age related uncertainties were described in the following themes: source of health challenge; health providers' age-related knowledge and skills; financial uncertainty; transition to retirement; appropriate long term housing and uncertainty over who would care for them. While not directly attributable to aging, the episodic nature of the illness left many with uncertainties related to when their next episode of illness would occur and often resulted in an inability to plan in advance. Results highlight the need to focus on the notion of successful and positive aging with the view to identifying effective interventions that reduce disability and enhance the overall health of older adults with HIV. This work builds on previous studies highlighting the central role of uncertainty in the disability experience by identifying age-related components specific to older adults aging with HIV.

Keywords: aging, HIV, disability, uncertainty, rehabilitation

With advances in combination antiretroviral therapy (cART), people living with HIV may survive for 30 to 50 years after infection (Antiretroviral Therapy Cohort Collaboration, 2008). The health-related consequences for people living with HIV include the adverse effects of cART, coupled with the natural processes of decline and deterioration associated with aging. There is an increased incidence of bone disease, cardiovascular disease, metabolic syndrome, cancer, earlier onset of frailty and an increased risk for neurocognitive decline among those aging with HIV (Guaraldi et al., 2011). Additionally, adults aging with HIV often experience added complexities related to the social determinants of health and the double stigma of ageism and living with HIV (Scrimshaw & Siegal, 2003). Collectively, these combined health-related consequences and increased longevity of HIV result in an increase in the disability experienced by older adults living with HIV.

Current models of disability recognize the contributions of age to the disablement process. For example, the World Health Organization's International Classification of Functioning, Disability and Health (ICF) conceptualizes a range of disability which considers how environmental and personal factors (including age) interact with the health condition to determine the level of functioning and health (WHO, 2001). The Episodic Disability Framework was derived from the perspectives of adults living with HIV and defines 4 dimensions of disability including any symptoms and impairments, difficulties carrying out day-to-day activities, challenges to social inclusion and uncertainty or worrying about the future that may fluctuate on a daily basis or over the longer trajectory living with HIV (O'Brien, 2008). Similar to the ICF, the Episodic Disability Framework highlights the manner in which environmental and personal factors including extrinsic contextual factors (i.e., social support, stigma) and intrinsic contextual factors (i.e., living strategies, personal attributes such as age) may exacerbate or

alleviate each dimension of disability. This Framework goes beyond other disablement frameworks to identify uncertainty as a key dimension of disability and incorporates the episodic nature of disability over time (O'Brien, Bayoumi, Strike, Young, & Davis, 2008).

Definitions of uncertainty in illness focus on complex cognitive stressors, a sense of a loss of control and an ongoing sense of not knowing (Johnson-Wright, Afari & Zautra, 2009). Illness uncertainty has been shown to be a source of stress and have a negative effect on a number of chronic and unpredictable illnesses including fibromyalgia (Johnson, Zautra & Davis, 2006), rheumatoid arthritis (Cleanthous, Newman, Shipley, Isenberg & Cano, 2012), systemic lupus erythematosus (Mattsson, Moller, Stamm, Gard, & Bostrom, 2011) and multiple sclerosis (Mullins et al., 2001). Higher levels of uncertainty have been associated with difficulty coping (Reich, Johnson, Zautra & Davis, 2006; Johnson et al., 2006), lower quality of life, (Braden 1990) and depression (Kroencke, Denney & Lynch, 2001; Reich et al., 2006).

Brashers et al. (1998) were the first to describe uncertainty related to HIV. They described how uncertainty manifested across four phases of the disease: at risk, diagnostic, latent and manifest. In 2003, Brashers and colleagues discussed how different illnesses possess unique types of uncertainty and highlighted stigma and social isolation as a source of uncertainty in those living with HIV. The Episodic Disability Framework considers uncertainty as it relates to the episodic nature of living with HIV - worrying about when an episode of illness might arise and what the consequences of it might be, as well as the impact of uncertainty on life decisions such as starting a family or returning to work (O'Brien et al., 2008; O'Brien, Davis, Strike, Young & Bayoumi, 2009). While this work provides a foundation for uncertainty in the context of HIV, the uncertainty specifically experienced by older adults aging with HIV is unknown. The purpose of this research was to understand the contribution of uncertainty to the disability

experienced by older adults living with HIV. We highlight the central contribution of uncertainty within a model of disability experienced by older adults as they age with HIV.

Methods

This research was a component of a larger qualitative study examining social participation and disability among older adults living with HIV. We recruited HIV positive women and men 50 years and older with the ability to communicate their experiences orally in English. Advertisements and brochures were posted in HIV clinics and AIDS Service Organizations (ASOs) and on ASO websites in two large urban centers in Southern Ontario, Canada. A research assistant conducted semi-structured interviews either face to face or by telephone. Interview questions explored various aspects of social participation, including self-care and household management; relationships with family, friends and romantic partners; work and employment; and access to health and social support services. A small honorarium was provided. An Advisory Committee consisting of persons living with HIV and representatives from ASOs across Canada provided oversight to the process and assistance with data interpretation.

Interviews were audio-recorded and transcribed verbatim. The data were analyzed using a constructivist grounded theory approach (Charmaz, 2006). NVivo 7 software (QSR International, 2006) was used to facilitate management of the data. To begin the analysis, each of the three investigators (PS, KO, SW) and the research assistant (NG) independently coded two manuscripts using an open coding technique. We subsequently met to establish a coding scheme, after which each of the remaining transcripts were coded independently by one of the researchers and the research assistant. We met periodically to review the coding, reconcile any differences and to revise the interview guide and coding scheme. Recruitment and iterative

analyses occurred until saturation of the data had been achieved. Following the coding of all transcripts the investigators met to identify themes and generate the initial theoretical model.

The final step consisted of a validity check phase whereby we invited a subgroup of interview participants to contribute to one of three focus groups in order to provide feedback on our initial model.

Ethical approval for the study was provided by the Faculty of Health Sciences Research Ethics Board, McMaster University, Hamilton, Ontario.

Results

Twenty-nine men and 20 women participated in the interviews. Interviews ranged from 30 to 90 minutes in duration. The mean age of participants was 56 years (range 50-74 years). The median number of years since HIV diagnosis was 13.5 years (range 6 months to 26 years). Three (6%) of the participants were employed full time, 10 (20%) reported part-time employment and 13 (27%) reported volunteer work. 18 (37%) reported themselves as retired or not seeking work, while the others reported wishing to work and/or actively seeking work.

Figure 1 depicts the model of disability experienced by older adults living with HIV. <<Figure1 here >> The inner circle represents the disablement experience; at the core of the experience is *uncertainty* with aging. Uncertainty had a bi-directional impact on all facets of disability. The *symptoms and impairments, difficulties with daily activities* and *challenges to social inclusion* are themes that are consistent with those of the Episodic Disability Framework. Disability is experienced in context with intrinsic or *personal contextual factors* and extrinsic or *external contextual factors* influencing all aspects of the disablement experience. The outer circle represents a number of elements associated with *time* which affect both the contextual

factors and the disablement experience. Details of the model have been described elsewhere (Solomon, O'Brien, Wilkins & Gervais, 2011).

Uncertainties related to aging were integral to this model. <<Figure 2 here>>

Participants were concerned about the *source of their health challenges* and whether what they were experiencing was a normal part of aging or something more sinister related to the virus:

“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?”

Many participants viewed themselves as the first cohort to “grow old” which lead to concerns as to whether their *health providers had age related knowledge and skills* to care for them:

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, you know, as a person who's been living with the disease for so long, that you will sort of accelerate with... cancers can accelerate. Cardiovascular disease can accelerate. Your bone density can decrease rapidly because of HIV and at that age. ... 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 was a concern particularly for long term survivors aging with HIV who did not expect a long life when initially diagnosed:

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.

Many of those who had been able to work were uncertain about the *transition to retirement* and whether they would be able to put in sufficient years to obtain a reasonable pension:

sure I feel left out when a lot of people are retiring and as I said, 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.

Others thought longer term and were concerned about *appropriate long term housing* for older adults living with HIV where they would not have to deal with stigma and homophobia:

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 are ready for even a gay senior to come in [to a long-term care facility].

Others were uncertain about *who would care for them* as they grew older; this was particularly true for those who had lost partners and friends to the virus. This participant felt that he could only rely on himself as he grows older:

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?

While not directly attributable to aging, the *episodic nature of the illness* left many with uncertainties related to when their next episode of illness would occur and often resulted in an inability to plan in advance:

If you're really, really dog tired, don't be foolish, like go lie down. I'd ride it out. But, and then of course you get up two days later and you're feeling on top of the world and what did I do?

The inability to plan for the future meant that some became disconnected from their friends and supports:

[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.

Discussion

This work builds on previous studies highlighting the central role of uncertainty in the disability experience by identifying age-related components specific to older adults aging with HIV.

Participants were concerned about their health provider's knowledge and skills and whether these were adequate to provide care for them as they grew older. As the long term consequences of HIV related disability and advances in medical management continue to emerge there will be a need for increased understanding of HIV related disability from all health professionals. The consequences of the increase in co-morbidities and concerns of "premature aging" associated with HIV are still emerging; these are likely to exacerbate the uncertainties related to health provider knowledge and source of the health challenge. A comprehensive

interprofessional approach to management can allow for the provider team to apply complementary knowledge and skills which will be necessary as HIV transforms into a chronic episodic illness in which no one health provider has all the expertise. (O'Brien, Wilkins, Zack & Solomon, 2010).

The uncertainty related to future caregivers relates to concerns about inadequate social support that have been widely discussed in the literature (Shippy & Karpiac, 2005). Older adults living with HIV are at increased risk for social isolation and risk of depression than their HIV-negative counterparts (Emlet, 2006). Older persons living with HIV tend to disclose their HIV positive status to fewer persons which may have implications on their willingness to seek appropriate supports (Nokes, 2000; Emlet, 2006). Emlet, Tozay and Raveis. (2011) found that the support received from meaningful relationships was important to developing resilience and went beyond the support provided by family and friends. For the first cohort of aging long term survivors, concern about caregiver support is particularly acute as many lost close friends early in the epidemic. Given that social isolation is a risk factor for aging in general, it will be important to develop programs to promote social interaction and support.

Similarly, the concerns related to finances and retirement support highlight the need to reform retirement benefit programs to enable those with episodic disability to remain in the workforce for as long as possible. We have found that disability programs create a significant disincentive to employment as often drug benefits are revoked (Solomon & Wilkins, 2008). Policies which promote flexible income support and employment and retirement programs are required.

Given the widespread stigma that people living with HIV continue to experience, fears of inadequate housing options are not unfounded. Our findings concur with those of Furlotte,

Schwartz, Koornstra and Naster (2012) who found that older adults living with HIV in a metropolitan area of Canada had concerns about being accepted into retirement homes and long term care facilities. Participants in this study also worried about barriers to subsidized housing associated with their age, HIV status and sexuality. While some have advocated for HIV specific residential housing, this could serve to further isolate individuals and increase stigma. The benefits of integrated housing models need to be evaluated. Brennan, Emler and Eady (2011) highlighted the exacerbating effect that ageism can have on HIV related stigma. They recommend that assessment of stigma be integrated into the regular screening and assessment process for older adults in order to gain an understanding of the effect of stigma on individual adults. From a broader perspective, there is an ongoing need for education and anti-stigma interventions.

Our findings have implications for practice and policy from individual and societal perspectives. The field of gerontology has explored the construct of “successful” aging but there has been little application to HIV (Depp & Jeste, 2009). Successful aging should consider those who experience disability and chronic illness yet maintain cognitive function, life satisfaction and social engagement. Indeed, there is an emerging literature that indicates older adults with HIV fare better than their younger counterparts (Depp & Jeste, 2009). Aging with HIV has been shown to be accompanied by wisdom, patience, contentment, moderation, and a greater respect for health and life – traits that enable older adults to cope well with their illness (Siegel, Raveis & Karus, 1998). Emler et al. (2011) found that resilience, a positive concept of aging, was present in a population of older HIV positive adults and related to self-acceptance, optimism, and self-management strategies. Lessons from the gerontology field can inform

interventions to promote successful aging; there is a need for capacity building between these two areas of study (Linsk, Fowler & Klein, 2003).

Our results highlight the need to focus on the notion of successful and positive aging with the view to identifying effective interventions that reduce disability and enhance the overall health of older adults with HIV. Previous studies have primarily focussed on interventions to promote positive coping and adaptation to uncertainty. Interventions focussing on improving individual coping strategies have been recommended though there are few rigorous evaluations in chronic and episodic illness. A recent randomized controlled trial evaluated the effectiveness of an uncertainty self-management intervention supplemented by regular telephone contact in adults with chronic obstructive pulmonary disease (Jiang & He, 2002). The intervention group showed significant improvement in uncertainty, coping strategies, anxiety and depression. Although promising, generalizability to an aging HIV population is unknown. Given the importance of self-management strategies in chronic illness and disability, it will be important to evaluate the effectiveness of these interventions in those aging with HIV.

Rehabilitation, defined as any services or providers that prevent or address impairments, activity limitations or participation restrictions experienced by an individual, can assist in managing uncertainty experienced by older adults living with HIV (Worthington, Myers, O'Brien, Nixon & Cockerill, 2005). Rehabilitation provides a bridge between biomedical and gerontological approaches in the area of HIV and aging and brings a broad understanding of disability. Rehabilitation professionals should be included in the health care team as a mechanism to reduce disability and uncertainty for older adults living with HIV. Leaders such as the Canadian Working Group on HIV and Rehabilitation have developed educational modules to

increase awareness of the role of rehabilitation in the management of HIV (Canadian Working Group on HIV and Rehabilitation, 2011).

The study is limited in that participants were relatively young with a mean age of 56 years and were primarily recruited from ASOs. The issue of what constitutes “older age” in those living with HIV continues to be debated. We used 50 years and older to be consistent with epidemiological reports (Public Health Agency of Canada, 2010). Sankar, Nevedal, Neufeld, Berry and Luborsky (2011) note the limitations of using chronological age as an indicator when trying to understand the process of aging. A rehabilitation perspective reinforces this notion and supports focussing on functional limitations and participation restrictions regardless of chronological age.

This study revealed the complexities of uncertainty experienced by adults aging with HIV. The participants described a complex experience with varying sources of age related uncertainty reinforcing the need for interventions at multiple levels. It is likely to remain difficult to disentangle the effects of the virus and those of aging given the complexities of the interaction between the two. Although it is clearly important to identify whether the source of the challenge is amenable to pharmacological management, from a disability perspective it is important to focus on managing the consequences of the challenge. If uncertainty is appraised as dangerous and a threat and left untreated it may contribute further to disability (Johnson-Wright et al., 2009). Thus it remains important for health and social service providers to understand how best to support individuals to cope with the uncertainty in their lives. Interprofessional practice and advocacy on individual and system levels are needed to combat the effects of uncertainty on the disability experienced by adults aging with HIV.

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Time

Time since Diagnosis

Episodic Nature of Disability

Age

Time on Medications

Time in Workforce

Contextual Factors

Aging & Disability

Symptoms and Impairments

Uncertainty with Aging

Difficulties with Day to Day Activities

Challenges To Social Participation

Intrinsic

Personal Attributes

Living Strategies

Extrinsic

Social Supports

Stigma

Figure 2. Sources of Uncertainty related to aging with HIV

Uncertainty related to Aging with HIV

