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Aging with HIV: A Model of Disability

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ABSTRACT

The purpose of this qualitative study was to develop a theoretical model describing the disability experienced by older adults living with HIV. Forty nine HIV positive men and women over the age of 50 years participated in in-depth qualitative interviews. Transcribed interviews were analyzed using grounded theory techniques. Uncertainty or worrying about the future was at the core of the model. Components of disability including symptoms and impairments, difficulties with day to day activities and challenges to social participation were experienced in the context of extrinsic or environmental factors (social support, stigma) and intrinsic contextual factors (positive living strategies, age). Time was an overarching component of the model. The model suggests areas for interventions to prevent or reduce disability related to the consequences of aging with HIV and improve overall quality of life.

Key words: aging, HIV, disability, rehabilitation, qualitative research

INTRODUCTION

The shift in the natural history of HIV has meant that people are living longer with HIV and associated comorbidities (1, 2). It is unclear whether HIV infection promotes “accelerated aging” or whether HIV is a risk factor which increases the likelihood of developing co-morbid conditions such as cardiovascular disease, cancer, osteoporosis, liver disease and functional decline (3). Regardless, as people living with HIV (PHAs) grow older, it is important to understand the health related consequences of HIV and associated comorbidities, otherwise termed as disability.

A number of theoretical models and disability frameworks convey the consequences of illness, beyond the traditional biomedical models of disease. The World Health Organization (WHO) developed a model of disability (*International Classification of Functioning, Disability and Health (ICF)*) that considers the consequences of disease at three levels including body structure or function (e.g. pain), activity (e.g. climbing stairs) and participation in society (e.g. working) (4). This model incorporates environmental and personal contextual factors that interact with and influence health. The *ICF* focuses on how individuals live with their health conditions and how these contextual factors interact with the health condition to determine the level of an individual’s function (4).

The *Episodic Disability Framework* was developed specifically from the perspective of adults living with HIV who described the disability experience as episodic and fluctuating over time (5, 6). The *Framework* includes four dimensions of disability: physical, cognitive, mental and emotional symptoms and impairments, difficulties with day-to-day activities, challenges to social inclusion, and uncertainty or worrying about the future. The *Framework* also highlights the importance of understanding how extrinsic contextual factors (e.g., social support, stigma) and intrinsic contextual factors (e.g., living strategies, personal attributes) exacerbate or alleviate each of the four dimensions of disability. This

Framework goes beyond the *ICF* to identify uncertainty as a key dimension of disability and incorporates the episodic nature of disability. It also describes in detail the living strategies that individuals use to alleviate disability (6). Hence, the *Episodic Disability Framework* is an ideal foundation for considering the health related consequences of HIV and aging.

As more individuals live longer with HIV there is a need for greater understanding of the consequences of aging with an episodic illness and resulting disability. The purpose of this research was to develop a theoretical model that describes disability experienced by older adults living with HIV. We developed this model by exploring the impact of living with a chronic and episodic illness from the older adults' perspective through a disability lens. In this paper we highlight the personal and environmental components of the model that affect disability experienced by older adults living with HIV.

METHODS

We conducted a qualitative study rooted in constructivist grounded theory (7). This approach allowed us to learn how, when and to what extent the phenomenon of aging with HIV was embedded in social situations and relationships (7). We recruited participants for a one-on-one interview through advertisements and brochures posted in waiting rooms and websites of HIV clinics and AIDS Service Organizations in southern Ontario. Eligibility criteria included HIV positive women and men 50 years of age or older with the ability to communicate their experiences orally in English. We obtained written informed consent from all participants.

Semi-structured interviews were conducted face to face or by telephone. The interview guide was derived based on components in the *ICF* and *Episodic Disability Framework* and included questions related to various aspects of disability, including daily activities (self-care and household management) and social participation (relationships with family, friends and romantic partners, work and employment, access to healthcare and social support services). Participants received an honorarium. A Community

Advisory Committee consisting of people living with HIV and representatives from AIDS Service Organizations provided oversight to the process and assistance with data interpretation. This study received Research Ethics Board approval from McMaster University, Hamilton, Ontario, Canada.

The interviews were audio-recorded and transcribed verbatim. Analysis of the interview transcripts began with an initial coding technique as described by Charmaz (7). Each of the investigators independently reviewed and coded three transcripts and then met to compare codes and develop an initial coding scheme. The investigators then coded the remaining transcripts independently with each transcript being coded by two investigators. The investigators met periodically to compare codes, reconcile differences and revise the coding scheme. Recruitment and iterative analysis continued until saturation of the data were achieved. Investigators then reviewed the codes and data to identify broader categories (7). The final step consisted of examining the relationships among the categories to develop the theoretical model. Our focus in developing the model was to highlight health challenges participants specifically attributed to older age or aging with HIV.

After the analysis of interview data, all interview participants were invited back to participate in one of three validity check focus groups to gather feedback on the preliminary model. At the focus group we presented a draft of the theoretical model, followed by a semi-structured focus group discussion. Specifically, we asked returning participants whether the model adequately captured their health challenges aging with HIV and discussed the utility of the model. Focus groups were audio-recorded and transcribed verbatim. We conducted a qualitative content analysis (8) of the transcripts to identify specific themes related to the feedback which informed final revisions to the model.

RESULTS

A total of 49 participants (29 men and 20 women) were recruited through the clinics and AIDS Service Organizations. Of these 46 participated in face to face and three in telephone interviews. Interviews ranged from 30 to 90 minutes in duration. See Table I for characteristics of participants.

Seventeen (13 men and 4 women) participated in a validity check focus group. The focus group participants confirmed that the model captured their experiences aging with HIV. Participant suggestions incorporated into the final model included: 1) moving uncertainty into the center of the disability sphere, 2) making arrows depicting the relationships among the components of disability bidirectional as opposed to unidirectional and 3) reconfiguring time as an over-arching dimension of the model.

The Model of Disability experienced by older adults aging with HIV is depicted in Figure 1. Disability is in the center of the model with uncertainty or worrying about the future at the core. There exists a bidirectional relationship between uncertainty and the remaining components of disability (symptoms and impairments, difficulties with day to day activities and challenges to social participation). Disability is experienced within the context of intrinsic or personal factors and extrinsic or environmental factors. Time emerged as an overarching component of the model which has an impact on the contextual factors and dimensions of disability. The contributions of the contextual factors and time specifically as they related to aging with HIV are described below with illustrative representative quotes. The central component of uncertainty has been described in detail elsewhere (9).

Intrinsic Contextual Factors

Positive Living Strategies

Selective social interactions

Participants recognized that social interactions were central to positive living strategies in order to alleviate their disability. With age, many felt they no longer had the energy levels of their youth and were selective of social activities in which they chose to participate. Many recognized that with age came a change in the activities with which a person engages and finds desirable.

“When you’re younger you’d do anything ... just everybody does everything. But by the time you’re 50, it’s a little less...you don’t do as much of the going out to the bars every night or going to the dances. When you’re older, it’s more of a social thing. You know, you... it’s the company. It’s the talking.

There was a subset of participants who recognized the importance of social connections but did not have the energy to maintain these. Others were selective about whom they chose to socialize with; with lower energy levels and days of ill health they wanted to be with “good quality friends”. Some found different ways to stay connected through email or by telephone. “...the people that I care about, I either touch base with email. Or once a month for instance I go out with one friend for lunch. I make time to see another one, you know a couple of times over the month...or just telephone. Just to keep in touch.”

Keeping a positive attitude

Many participants appeared to have accepted that they were living with HIV and had developed a positive attitude towards aging. They acknowledged they had “a completely different mindset” than they did in early adulthood. They spoke of living “day by day” and recognized that with aging comes wisdom and appreciation of “small things.” They had confidence in the health care system and the health professionals who had helped them get to this stage of their lives. To many, growing older was a surprise so they took joy in aging and looked forward to growing old.

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

Maintaining a sense of control

Many participants talked about maintaining a sense of control over aging with HIV and their fate.

“I know that I’m in control. It’s [HIV] not in control of me. I’m in control of it. And hopefully it’ll remain like that.”

There were a number of strategies that participants used to maintain the sense of control. For some it was learning as much as possible about their illness. For others the sense of control came from trying to live a healthy lifestyle. Others valued partnerships they had developed with health professionals and had learned to advocate for themselves.

“... you recognise that a person living with HIV AIDS has as much control in determining their destiny of the disease as the medical profession. So, it’s got to work hand in hand.”

Focussing on other aspects of life beyond HIV Status

Participants described living strategies in which they deliberately chose to focus on other aspects of life rather than solely on their HIV status. Though many recognized the adversity in their lives and the episodic nature of their illness, they had learned not to dwell in the past and tried to maintain a sense of moving forwards in their lives. Many described having to “force” themselves to be active in spite of the “bad days” and difficulties with activities.

“I don’t think it would be good to just sit down and not walk anywhere or do anything.

As much as some days I’d like to, but I force myself. “

Another strategy was related to keeping a busy, active life. This meant different things to different people. For some, volunteering helped participants to shift the focus away from their needs. For others, it was keeping physically active.

“...running to the grocery store to get the stuff for the [AIDS Service Organization]. You

know, I love doing that. I mean, even though my legs are bad I still love doing it. I still

love walking...”

External Contextual Factors

Social Supports

Participants described social supports in a number of ways. Some had very practical needs related to food banks and transportation. Some of these needs were met by family or friends, while others relied on AIDS Service Organizations.

“(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.”

Others appreciated that the emotional support they received from others was important to maintaining a positive attitude.

“It helps a lot because, it helps the loneliness. So you know, so I’m not sitting and staring at the four walls. I know I can pick up the phone and just call one of them. I kinda go through my head “who can I call, who can I call?”

Participants appreciated that partners provided much needed social support. Those who did not have a partner felt that opportunities for developing intimate relationships decreased as they aged. Some worried about social isolation as they grew older.

“... I need a partner. As I’m getting older, I need somebody at my side. I don’t want to be old and ... and sitting on the stoop alone. I want a partner.”

While some had developed a sense of independence as they aged and were not concerned about being in a long term relationship, others had resigned themselves to a lonely future without a partner.

“Because of being HIV positive and then of course being 60 plus, you go through a whole period of realization that you are going to spend your senior years alone. You’re not going to have a significant other in your life, so and that is an emotional ride. There’s days, where it doesn’t matter, and so on and so forth and there’s days where you say, it’s going to be a lonely existence.”

For some, family members were a major source of social support. Others were estranged from their families for many years as they had been rejected by their families when they disclosed their sexual orientation or because their family situation had been precarious. Some women found that rather than receiving support from their families they were the ones who had to provide support – to aging parents.

Another venue for social support was AIDS Service Organizations. Many appreciated the services provided (e.g. food programs,) but participants noted a lack of services for older adults. There was a sense that the needs of older adults were much different from those of someone in their thirties.

“A thirty-five year old person who’s pretty healthy has nothing really in common with a sixty or fifty-five year old person who’s pretty healthy. Same with HIV - thirty-five with HIV, sixty, fifty-five HIV: nothing in common other than you’ve got the same disease.

Right? But other than that, your needs are going to be totally different. It's just one more quality. It's like expecting all women to have everything in common."

Age-related Uncertainty

Age related uncertainty arose from a number of sources which have been described in detail elsewhere (9). Participants were concerned about whether their health challenges were related to the normal aging processes or to the virus and if their health care providers would have adequate knowledge and skills to care for them as they aged. Uncertainty related to long term financial status and retirement was pervasive as were concerns related to access to suitable long term housing and availability of caregivers as they grew older.

Age-related Stigma

Participants experienced stigma in many ways. They described multi-layered stigma related to HIV status, age, gender, sexual orientation and as a visible minority. Participants described becoming increasingly aware of stigma related to aging. This participant had experienced a negative reaction to his survival to an older age:

"I'd say it does affect me because people sit there and go "Like, you're old and you've been positive and you should be dead by now."

While many worried about the future and age related stigma, few had experienced it. Participants were fearful of what age related stigma might bring.

"I find myself fearing a lot of the unknown, getting older I feel that I'm losing my traction. That you know, people may begin to look at me as older. You see people that are getting older you view, you view people getting older and people lose interest in them. Being HIV living with that stigma makes me feel isolated and fearful."

Time

The influence of time on the disability experience was multifaceted and affected the contextual factors and dimensions of disability. While participants recognized that chronological *age* had a direct impact on age related disability other factors related to time emerged from their experiences. Those who had been living many years with HIV had a perspective on the *time since diagnosis*. Participants reflected on how they had to deal with a terminal diagnosis in the 1980's and 1990's and did not consider the prospect of growing old.

“I think for us older ones, it'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.”

Time was also a factor in the *episodic nature of disability* in which participants experienced unpredictable and fluctuating periods of good and ill health. The sense of uncertainty seemed to be exacerbated by the episodic nature of the illness over time.

“It's like if I can get the energy to get out, then all of a sudden I pick up and I just try and do as much as I can. While I'm out because I don't know if the next time is ... I'm going to get out.”

The amount of *time in the workforce* had a direct impact on the participants' financial status and planning for the future. Some participants who were out of the workforce for many years did not have pensions. Others wanted to work but experienced barriers related to the unpredictability of their illness, fear of losing benefits, lack of training and/or stigma.

“I think, employment wise because I’m older, I face much more...well, if not outright discrimination, [but]certainly I am at a disadvantage in the labour market. “

Participants often compared themselves with others of the same age who were not HIV positive. They recognized that it took a longer time to recover from illness and injury and there was a sense of *growing old faster or accelerated aging with HIV*.

“But what scares me about aging is its coupling with HIV. All of those things that people didn’t worry about until they got to be sixty-five or eighty-five are all being accelerated and all being pushed back in the time line of people’s lives so that you’re getting forty year olds and fifty years olds experiencing the aging complexities that historically people in their seventies and eighties were experiencing.”

Participants felt that the adverse effects of medications contributed to their aging experience and that there was a relationship between *length of time on medication* and disability. They recognized improvements in pharmacological management since the beginning of the epidemic but longer term survivors seemed resigned to the accumulation of side effects over time. They worried about how long the effectiveness of the medications would last.

“Having HIV tends to limit the amount of time that you have because you never know if and when your current drug regimen’s going to continue to keep the virus at bay, and then you’re going to be right back at square one on death’s door.”

DISCUSSION

This model builds upon the Episodic Disability Framework through describing a model of disability specific to the context of older adults with HIV. While a component of the *Episodic Disability Framework*, uncertainty related to aging was at the core of disability described by older adults with HIV.

This suggests that health and social service providers have an important role to play supporting individuals to cope with the uncertainty in their lives. The most notable differences in this model were the elements of time that surrounded and influenced the entire disability experience. Chronological time including time since diagnosis and time on medication had an effect on symptoms, daily activities and social participation. Time in the workforce affected current available finances and contributed to uncertainty, financial resources and planning for the future. The episodic nature of the disability emerged over time and contributed to uncertainty as did the sense of growing older faster or accelerated aging with HIV. Others have found that adults living with HIV have reoriented the meaning of time to regain a sense of control by living in the moment rather than focussing on an uncertain future (10) or by valuing the quality of their time rather than quantity (11). In our model, time is an overarching component influencing the contextual factors and disability. Participants are aware of the passage of time and have a sense of growing older. The relationship is complex and points to a need for research to better understand the challenges of aging with the episodic and unpredictable nature of HIV. As with aging, episodic disability is a temporal process and the consequences and contributions to disability can only be illuminated through longitudinal study.

Our findings highlight the complex and multidimensional nature of stigma as it specifically relates to older adults with HIV. The understanding of how ageism interacts with other sources of stigma is in its infancy. Given the relationship between stigma and depression and the increased social isolation experienced by older adults living with HIV, it will be important to understand how ageism affects the overall disability experience (12). Brennan et al note the exacerbating effect of age-related stigma on HIV stigma (13). They call for integration of stigma assessments by those working in HIV and gerontological fields. Most of the participants in our study had not directly experienced ageism; this could be due to their relatively young median age of 56 years. However, many expressed a fear of age-

related stigma. In our model stigma is an important component of the external environment affecting all components of disability, reinforcing the need for widespread stigma interventions.

Social support is a social determinant of health that has been examined extensively in both the gerontological literature and in adults with HIV under the age of 50 years (14). An emerging literature has focussed on older adults living with HIV. Scrimshaw and Siegel identified seven barriers to social support in older adults with HIV of which only one, ageism, was unique to older adults (15). However they hypothesized that the barriers common to all ages may be more prevalent or severe in older adults living with HIV. Emler's work supports this notion (16). He compared the social networks and social isolation among older and younger HIV positive adults and found that a higher percentage of older adults were at risk of social isolation. Our participants recognized the need for social support but understood the importance of quality supports and became selective about with whom they would engage suggesting engagement in an active problem solving approach to manage aspects of social participation.

Participants used a combination of living strategies in order to address the challenges of aging with HIV. Many participants spoke of being positive about growing older and identified strategies that combated uncertainty by maintaining a sense of control. These positive living strategies are similar to strategies of self-acceptance, optimism, and self-management that promote resilience a positive concept of aging (17). While it was not our intent to specifically identify strengths and resilience of older adults living with HIV; these emerged through the development of our model. We support recommendations for further research to understand successful aging among adults living with HIV in order to identify those at most risk (18). The field of gerontology has explored the construct of "successful" aging but there has been little application to HIV (19). Our work suggests that focussing on the episodic nature of the illness and the impact of uncertainty on the disablement process are key to increasing this understanding.

Our study possesses some limitations. First, participants were relatively young. The definition of “older age” in the context of HIV continues to be debated. We used 50 years and older to be consistent with epidemiological reports (20). There is evidence for differences in age-related challenges between adults living with HIV in their 50’s and those in their 60’s, suggesting the importance of examining the influence of age by decade rather than as a heterogeneous group over the age of 50 (21). In contrast, the limitations of using chronological age to examine health and social outcomes among adults living with HIV was noted in a 2011 review by Sankar et al. (22). Second, our sample was recruited primarily from AIDS Service Organizations in southern Ontario. Users of AIDS Service Organizations tend to reside in urban areas and thus these findings may not be applicable to older adults living in more rural areas who may experience more social isolation and fewer HIV-specific supports. Some of the components of our model may not be related to aging and have been highlighted in people living with HIV under the age of 50 years. This reinforces the difficulty in separating age related consequences from HIV related consequences (23).

While the element of time is non-modifiable, other extrinsic and intrinsic contextual factors of this model suggest areas in which interventions may be implemented in order to prevent or reduce disability experienced by older adults with HIV. The consequences of disability can be addressed through rehabilitation, a dynamic process aimed at maintaining, restoring and enhancing quality of life (24). In spite of the potential role of rehabilitation, few rehabilitation professionals are involved in rehabilitation care (25). Although treatment guidelines for older adults living with HIV refer to issues such as frailty and functional capacity and highlight common co-morbidities that are amenable to rehabilitation, rehabilitation strategies are largely absent (25).

HIV has become a complex chronic disease which cannot be understood by studying isolated parts (26). There is a need to understand the consequences of aging with HIV and the impact on quality of life. This

study is the first to portray a model of disability experienced by older adults with HIV. The complex relationships in the model reinforce the need for a multifaceted comprehensive approach incorporating rehabilitation in the care, treatment and support of 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