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## A Longitudinal Qualitative Study on Living Strategies for Disability in Men Aging with HIV in Ontario, Canada

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**A Longitudinal Qualitative Study on Living Strategies for Disability in Men Aging with HIV in Ontario, Canada**

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Keywords: HIV, episodic disability, longitudinal analysis, qualitative research

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## ABSTRACT

**Objectives:** To examine the living strategies used by older men living with HIV to deal with the episodic nature of disability, and associated uncertainty, over time.

**Design:** Qualitative longitudinal study in which men living with HIV were interviewed on four occasions over 20 months.

**Setting:** Men were recruited from HIV community organizations in Canada.

**Participants:** 14 men with a median age of 57.5 years and median time since diagnosis of 21.5 years.

**Results:** Five themes depict the living strategies used to deal with the episodic nature of disability and uncertainty over time. Actively engaging in problem-solving by prioritizing and modifying activities and avoiding stress, advocating for support, being positive and future oriented, engaging in healthy pursuits and providing social support to others helped men to mitigate their disability. By following participants over time, we were able to gather insights into triggers of episodes of disability, perceptions of the success of implementing their living strategies and avoiding uncertainty.

**Conclusions:** Participants used living strategies to deal with uncertainty and mitigate episodes of disability over time. This study supports the importance of programs that promote self-management for older men living with HIV through helping them identify triggers of disability, setting realistic goals and problem solving. These may help build self-efficacy, increase sense of control, and decrease feelings of uncertainty and episodes of disability.

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**STRENGTHS AND LIMITATIONS OF THIS STUDY**

- We conducted a longitudinal qualitative study of the living strategies used by older men living with HIV over time.
- We interviewed participants on 4 occasions over a 20 month time frame and achieved a 100% retention rate.
- Strengths included prolonged engagement participants over time and use of a disability lens as a foundation for this research.
- Limitations include an independent community-dwelling sample of long term survivors which may be better able to access supports and engage in positive living strategies.

## INTRODUCTION

In resource rich countries where people living with HIV are growing older and attaining a near normal life span, there has been increased recognition of HIV as a chronic illness that may result in health challenges, or disability.[1-4] Older adults ( $\geq 50$  years) living with HIV may experience disability related to the virus, side effects of medication, multimorbidity, and natural consequences of aging.[5] The disability experienced by people living with HIV is often episodic in nature, associated with unpredictable fluctuating periods of good and ill health.[6] The Episodic Disability Framework, derived from people living with HIV, includes four dimensions of disability: symptoms and impairments, difficulties with day to day activities, challenges to social inclusion and uncertainty about the future that can be influenced by extrinsic and intrinsic contextual factors.[6]

While a key dimension in the Episodic Disability Framework, uncertainty resulting from the unpredictable fluctuations in health is also viewed as a defining feature of aging with HIV that can increase anxiety of everyday life for people living with HIV.[7] Uncertainty is at the center of a model of disability influencing symptoms, activity and participation levels for older adults living with HIV.[8] Further modeling of dimensions of disability has suggested uncertainty is a direct and strong predictor of mental and emotional health challenges and challenges to social inclusion for people living with HIV.[9] Age-related uncertainties include worries about the source of health challenges, concerns about health providers' knowledge of HIV, financial and retirement concerns and long-term care and housing options.[10] Furlotte and Schwartz[11] reinforced that uncertainty contributes to mental distress among older adults living with HIV. Kylma et al[12] hypothesize that uncertainty can be both negative and positive; if combined with fear it may lead to hopelessness, while combined with wishing, is related to hope.

While a number of studies have reviewed how people living with HIV cope with a chronic illness,[13] few have addressed how they deal with the episodic nature of HIV and associated uncertainty. Brashers et al[14] found that social support helped people living with HIV to manage uncertainty through a variety of strategies such as assisting with information seeking, providing instrumental support and offering acceptance. Uncertainties related to HIV are perceived differently by health professionals and people living with HIV, with professionals viewing uncertainty as related to a lack of scientific knowledge, and people living with HIV and policy makers viewing uncertainties as chronic stressors.[7]

In the Episodic Disability Framework, living strategies are intrinsic contextual factors that may interact and influence dimensions of disability including uncertainty.[6] The term living strategies was derived from the perspective of people living with HIV[6] and is analogous to coping in the context of HIV.[15] Living strategies are differentiated from coping in that these can have both positive and negative influences on health.[15] A survey comparing the frequency of living strategy use between age groups found that a greater proportion of older adults with HIV ( $\geq 50$  years) engaged in living strategies focussed on maintaining a sense of control over one's health and adopting positive attitudes compared with younger adults with HIV.[15]

Studies examining coping and living strategies in older adults living with HIV have predominantly been cross-sectional in nature. Few have examined how the episodic nature of the disability, including the dimension of uncertainty, may be influenced by living strategies used by people living with HIV. Episodic disability is a temporal phenomenon best understood through longitudinal inquiry. Our goal was to examine the living strategies used by older men living with HIV to manage with the episodic nature of disability, and associated uncertainty, over time.

## METHODS

We conducted a longitudinal qualitative study involving a series of four semi-structured face-to-face interviews with older men and women living with HIV at five-month intervals. Participants were recruited through HIV community organizations in Southern Ontario, through pamphlets onsite and recruitment notices on websites. Eligible participants were 50 years of age or older, who were diagnosed with HIV for more than 6 years. There are gender differences in the strategies people living with HIV use to deal with their health challenges.[16-18] Thus, in this study we present the analysis of the participants who identified as men.

We used the Episodic Disability Framework[6] to guide the semi-structured interviews. All interviews were conducted by the same investigator. During the first interview (Time 1), we asked participants to provide a general description of their health challenges (or disability) including physical, cognitive, mental and emotional symptoms and impairments, difficulties carrying out day to day activities, uncertainty and worrying about future health, and challenges to social inclusion. The challenges were then explored in detail, probing for whether these were episodic in nature, and the living strategies used to address their health challenges (including uncertainty). In subsequent interviews we explored the dimensions of disability identified in Time 1 and asked participants to consider what changes occurred, how they occurred, and how these changes affected their functioning and health. Our design allowed for emergent themes to be discussed over time. Participants received an honorarium at the completion of each interview.

Analysis: All investigators contributed to the analyses. Investigators had complementary areas of expertise in gerontology, HIV, and disability. Interviews were audio-recorded, transcribed verbatim and entered into QDA Miner version 5 for data management.[19] Longitudinal qualitative analysis requires summary and comparison of data both longitudinally and cross-sectionally.[20] Initially, two investigators (RM and MS) independently carried out line by line coding of all four transcripts from one



participant and developed a code book to guide our analysis.[21] The analysis focused on identifying disabilities, the living strategies participants used to deal with their challenges, any triggers of episodes and whether the disability was episodic in nature (varied over the interviews). Codebook development was an iterative process involving ongoing discussion and revision. All transcripts from three participants were then reviewed independently with a subsequent meeting with a third investigator (PS) to refine the codebook and resolve discrepancies. The remaining transcripts were then each independently coded by two investigators (RM and MS) using the codebook. As we interviewed each participant on four occasions, we were able to follow the strategies used to address health challenges (or disability) and uncertainty over time. We developed an in-depth summary of each participant's disability experiences over time and compared these across participants to identify themes. All investigators reviewed and came to consensus on the final themes.

Research Ethics Board approvals were received from McMaster University and the University of Toronto. All participants provided written informed consent.

### Patient and public involvement

This study is a part of a larger study in which a community member was included on the research team as one of the investigators. He reviewed and provided input on the research question and design prior to grant submission. Results of this study will be distributed to participants who indicated that they would like a copy of the research findings and provided contact information.

## RESULTS

Fourteen men volunteered to participate in this study and completed all four interviews. Participants' age ranged from 50-73 years (median: 57.5 years; IQR 53.3-65.3) with a median time since diagnosis of 21.5 years (IQR 19.8-25). The median total symptom score on the HIV Symptom Index[22] was 10.5/20 (IQR 8-15), and the median bothersome symptom score was 10.5/20 (IQR 5.8-12). Nine

men reported being single, four were living with a partner and one was divorced. We identified five themes which illustrated the living strategies used by participants to manage uncertainty and minimize disability over time.

### **Prioritizing Activities, Modifying Expectations, Avoiding Stress**

Participants actively engaged in problem-solving and developed strategies to manage their disability. They experimented with many strategies over time and were able to evaluate the most successful options. Participants described cognitive strategies to avoid dwelling on uncertainty and worrying about the future, as stated by this participant,

...rather than worry about what might, what could (be)...(I am) just dealing with the thing when it comes up. I seem to be much better at not worrying about it or not getting depressed over it. (Participant 5, age 66; 20 years living with HIV)

Participants described how they prioritized needs and activities, and set goals. For example, many were on a limited income and tried to proactively budget so that they were able to meet their nutritional and social needs. One man described how he used a phone app to manage his health issues. Key to the ability to prioritize activities was participants' acknowledgment of the need to accept limitations. For example, modification of tasks was a way to live with fatigue. This participant recognized his limitations and described how he felt it was possible to do activities he did when younger: "(if you) change your strategy of how you accomplish it." (Participant 6, age 65; living with HIV for 20 years).

Participants spoke of needing a "different approach", adjusting their expectations of what they could accomplish. One participant described how he had stopped volunteering at a hospital because he found it exhausting stating, "at this point I need to give more to myself than to others." (Participant 11, age 51; 25 years living with HIV). Another participant described how letting "stuff" pile up could trigger

depression and how he learned to do a “cost-benefit analysis” of whether he should engage in an activity:

I’m getting much better at doing (a cost-benefit analysis) and saying, “okay, it’s of more benefit for me to do it, even though it’s going to be a little bit uncomfortable, than it’s going to be not to do it... (Participant 5, age 66; living with HIV for 20 years).

Often a key to solving problems was the ability for participants to identify triggers of episodes of disability or ill health. Participants recognized stressors in their lives related to their illness, such as life and family situations which were triggers for mental health issues and could lead to activity limitations and participation challenges. Proactive stress avoidance was common. Participants would avoid interacting with individuals who were not contributing positively to their emotional well-being.

Through increased awareness of triggers of episodes of disability, many were able to prioritize activities, avoid uncertainty and mitigate an exacerbation. Weather was described as a trigger of depression and knowing this enabled participants to “deal with it”. Fatigue was a common experience and participants described how they needed to be “careful” to ensure that they had adequate energy levels. This man described how he had a 3 day regime to ensure he was rested and avoided feeling depressed.

(you can) roll around and relax and eat chocolates and feel sorry for yourself...but then after the third day you’ve got to get out of your environment whether it be your apartment or your head space and try to just go for a walk or do a bit of exercise. (Participant 3, age 61; living with HIV 30 years)

One participant identified triggers for increasing musculoskeletal pain related to arthritis and how he modified his lifestyle to “keep the pain at bay.” Others used functional aids to adapt, such as walkers, orthopedic shoes or inserts and “diabetic socks” to help maintain their activity levels. One man

got a continuous positive airway pressure (CPAP) machine during the study to help with sleep and fatigue and felt he was “feeling more alert” as a result.

### **Self-Advocating for resources, care and support**

The ability to advocate for resources, both medical and financial, was a key strategy to manage challenges from disability. Participants described how remaining active and involved with their health provided a sense of control and stability which circumvented feelings of uncertainty. Participants took their role in managing their health seriously with many taking an active role in learning about their medications and side effects, management strategies and co-morbidities. They negotiated around how often they would need to access the health system and their preferences for health providers. This man described the role he preferred his family doctor to play in management of his overall health,

I’ll just talk to him next time I see him and say, “You’re my family doctor. I want you as my family doctor, you help me with a number of problems. But I don’t want you to be my HIV doctor. Period. I am the center of my care plan, not you. (Participant 1, age 73; living with HIV for 21 years).

Participants sought out information to learn about their health from the internet, community HIV organizations and health providers to play a more active role in their management. Negotiating care around multiple providers was often challenging. One man described how after a prostate cancer diagnosis he felt he needed to meet with the specialist and his family physician separately so that he could make the most informed decision about treatment options. Participants recognized that it was important to be organized for health care visits, which included coming prepared with questions.

Participants were knowledgeable about their medications related to HIV management, pain management and other co-morbidities including diabetes. They advocated with their physicians about

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3 how to decrease their pill burden. One man spoke at time 3 of wanting to be off all psychiatric  
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5 medications and reported he had done so at time 4.  
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8 Participants also advocated for supports and resources to improve their health and quality of  
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10 life. Several lived in subsidized housing and described working with tenant associations to deal with  
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12 adverse situations or negotiating for changes to ensure that their housing accommodated their  
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14 disability. Others advocated for funding for volunteer programming and resources through community  
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16 agencies.  
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20 **Looking to the Future with Positive Outlook**  
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23 Participants' perspectives and acceptance of aging with their illness allowed them to be positive  
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25 and future-oriented. Participants planned on travelling, fixing up their apartments, starting to exercise  
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27 and diet, and becoming involved in volunteering. Participants were pleased to be growing older and  
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29 thought beyond their limitations and past disappointments. One man was excited about a new romantic  
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31 relationship as he thought this would not happen at his age; as he stated, "this stuff doesn't happen to  
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33 me." Although older, many contemplated returning to school or retraining for a new job.  
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37 The longitudinal design of the study allowed us to observe some participants' plans and goals  
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39 come to reality. One man dreamed of going to New York to see the ballet and the opera and at the  
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41 second interview stated he had achieved his goal. Another man's goal of volunteering emerged as an  
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43 opportunity to be on panel discussions and developing videos for health science students. One man set  
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45 a goal of getting a bicycle and was able to acquire one between the second and third interviews.  
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47 Another planned to increase his walking and persisted "rain or shine".  
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51 This positive outlook was associated with acceptance of growing older as noted by this man: "(I  
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53 am) not thinking of aging, being old as an illness. It's simply a part of living." (Participant 1, age 73; living  
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55 with HIV 21 years).  
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As long-term survivors with HIV, many participants reflected on their past challenges and contrasted this with their current status:

I think it's wonderful the medications that we have now, so that they can maintain a fairly substantial level of good health, for the long-term survivors (participant 6, age 65; 20 years living with HIV).

### Engaging in a Healthy Lifestyle

Twelve men described positive lifestyle choices and expressed their desire to continue to live a healthy life as they aged with HIV. Many were committed to healthy pursuits as a way of coping with aging, HIV and comorbidity-related disability. Exercise and remaining physically active was the most common strategy for maintaining health. One man with limited mobility was committed to doing exercises in bed and walking with his walker. With limited income, some participants found that walking was the most affordable exercise regime. As this man stated, "I'm staying true to my exercise programme and eating healthy and getting my rest as I'm supposed to...I'm managing quite well and feeling...enjoying good health". (Participant 6, age 65; 20 years living with HIV)

Diet and weight concerns were expressed by many. Many had goals of losing weight and some succeeded over time. One man used a spreadsheet to count calories. Most tried to make healthy choices and be disciplined as this man stated, "I just do everything in moderation". Participants sought dietitian advice for co-morbidities such as diabetes and hypercholesteremia.

Participants linked exercise and diet as a weight loss strategy. Some joined the YMCA or a local gym. Many were committed and recognized when they needed external motivators to engage regularly. Several attributed improvements in their mood and musculoskeletal pain to regular exercise. One man started an outdoor walking program for older adults with cardiac problems. Another man received a

bicycle which “changed his life”. Another man joined a fitness study which included the services of a fitness coach which he found very motivating.

**Valuing Reciprocity of Social Support**

Participants valued social support to help them deal with dimensions of disability (including uncertainty) and often sought to extend their circle of support. Support was received from many sources including family and friends, HIV community organizations, work and volunteer relationships, health and social services and virtual networks. HIV community organizations were described as the “main source” for support and as ways to access free activities (yoga class) or health and social services (nutritionist). Family members were key supports, though several participants described dysfunctional family relationships over the duration of the study. Two participants stated that their support was “sufficient” and that they preferred being alone.

The desire to also provide social support to others was an important aspect in the lives of many of the men. When asked whether it was difficult to support others this man remarked, “it takes your attention away from your own shtick.” As participants were older, some dealt with the complexities of providing support to aging parents. HIV service organizations provided a safe outlet for interaction and participants often volunteered to give back to their community. Several men participated in a “buddy program” through their local HIV community organization with one man describing his role as a “friend counsellor”. Participants described how friends supported each other, “I still have a small cadre of friends that...we tend to interact when one of us gets sick.” One man described how his friends and family encouraged him to “stop focussing on other people” and attend to his own needs. Another man described a complex relationship he had with an addicted homeless youth and how he tried to care for him.



Participants also experienced challenges seeking out social support; describing difficulty making new friends, especially someone in their “age bracket”. However, over time some participants were able to develop new networks by joining organized activities such as a swimming group, seeking out walking “buddies” or by exercising at the YMCA. Some were reluctant to ask for practical support as stated by this man,

I’ve learned, this was a hard one for me, I’ve learned to ask for help. My friends have all said to me that, you know, don’t be shy to say could you come over and give me a hand doing windows or something like that. (Participant 6, age 65; 20 years living with HIV)

## DISCUSSION

Overall this study portrays a positive picture of older men living with HIV who integrate living strategies into their lifestyle to address their disability over time. Actively engaging in problem-solving by prioritizing and modifying activities and avoiding stress, advocating for support, being positive and future oriented, engaging in healthy pursuits and providing social support to others helped men to mitigate their disability. By following participants over time, we were able to gather insights into triggers of episodes of disability and their perceptions of the success of implementing their living strategies and avoiding uncertainty.

While many studies of people living with HIV have identified the value of *receiving* social support, few have examined the benefits of *providing* social support. Our findings that men valued reciprocity of social support reinforces Emlet et al’s notion of generativity or a sense of well-being for future generations as a component of resilience or the successful adaptation to negative life events.[23] Participants in our study described reasons beyond “giving back” to the HIV community including



pragmatic reasons such as caring for one’s parents and as a way of diverting attention from their own problems.

Rosenfeld found that even PLWH with strong social support from those who are HIV negative require the mutual understanding that comes from individuals living with HIV and HIV community organizations.[24] The important role of HIV community organizations in facilitating links to social supports, and providing opportunities for adults aging with HIV to reciprocate their support to others, was reinforced in this study. Interestingly, avoidance of HIV support groups was identified as a strategy to support well-being by shifting the focus away from HIV.[24] This emphasizes the need for HIV community organizations to understand clients’ needs and goals and tailor their support services accordingly.

Although a well-established approach for many chronic illnesses, self-management programs for people living with HIV are still emerging as a way to develop living strategies. This study supports the importance of programs that promote self-management for people living with HIV in several ways. Participants in this study learned to identify triggers of episodes of illness or disability to proactively mitigate severity of disability. This was important for setting realistic goals, a key component of self-management programs,[25] and for prioritizing and modifying their tasks and activities. Living strategies that include problem-solving can help build self-efficacy, increase one’s sense of control and mitigate feelings of uncertainty.

The ability to communicate effectively with health providers and advocate for increased access to health services is another common component of self-management programs.[25] The participants were knowledgeable about HIV and the health system and described how they were able to advocate for their health and disability needs over time. Health literacy is important to be able to navigate the health system and knowledgeably express one’s needs.[26] It is possible that many of the long-term

1 survivors had to learn to advocate for supports at a time when knowledge of HIV was emerging and  
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3 stigma was widespread. Regardless, increasing HIV knowledge and assisting people living with HIV with  
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5 communicating their needs may be an important goal to enable better navigation of the health system  
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8 for timely and appropriate access to resources.  
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13 The strategy of remaining future oriented with a positive outlook may be associated with  
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15 resilience in those aging with HIV. Resilience may be a modifiable factor which is protective against  
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17 cognitive and functional decline people living with HIV.[27] Although further research is required to  
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19 determine the causal relationship between resilience and function in people living with HIV, evidence in  
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21 other populations suggests that interventions targeting resilience (e.g. positive reframing and coping)  
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23 may be an important component of managing disability in older adults with HIV. Self-efficacy is a  
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25 protective factor which may moderate the negative consequences of living with HIV.[28] Self-  
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27 management strategies that increase self-efficacy for dealing with the episodic nature of HIV and  
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29 associated uncertainty, and promote positive coping, may help develop resilience living with HIV.  
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34 Although present, uncertainty did not play as prominent a role in participants' disability  
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36 experiences, in contrast to other studies.[10] It is possible that the proactive living strategies, many of  
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38 which had been well-established and in use for some time by the men, and their attempts to pre-  
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40 emptively identify triggers of disability helped them to avoid fluctuations in their health challenges and  
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42 avoid uncertainty. People living with HIV also experience varied trajectories of episodic disability, one of  
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44 which is described as stable.[29] Hence it is also possible that these participants experienced little  
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46 fluctuation in their disability and less uncertainty over time.  
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52 Strengths of this study include the prolonged engagement and retention of all participants over  
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54 the duration of this study which gave us insights into the living strategies used by people living with HIV  
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56 over time. In addition, the use of a disability lens as a foundation for this research allows for  
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3 understandings into the consequences of comorbidities and how environmental and personal factors  
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5 influence living strategies over time.  
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8         This study is limited in that participants were recruited from HIV community service  
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10 organizations and thus may be a more independent community-dwelling sample better able to access  
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12 supports and actively engage in positive living strategies. As time since diagnosis has been shown to be  
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14 positively associated with resilience and mastery, an affective resource that helps develop self-  
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16 control,[30] these long-term survivors may have been better able to cope with their episodic disability  
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18 over time.  
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22         This research has several clinical implications. Self-management is recognized as an important  
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24 element for developing long-term living strategies to manage chronic conditions, including HIV.[25]  
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26 Increased access to health services and improved communication with health providers are common  
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28 outcomes of self-management programs.[25]To achieve favorable health outcomes aging with HIV,  
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30 people living with HIV require training and support to effectively self-manage their health, communicate  
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32 their potential needs to access services health services, and participate in shared decision-making with  
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34 their health care providers. Cognitive approaches which promote positive living strategies, such as  
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36 positive reframing, should be reinforced by health providers.  
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41         Participants did not link two of the living strategies, valuing reciprocity of social support and  
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43 looking to the future, directly to dealing with the episodic nature of disability. It may be that these  
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45 strategies are dispositional in nature and represent an overall approach to dealing with health  
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47 challenges or disability. Being future oriented and with a positive outlook assists in dealing with  
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49 adversity and promotes successful aging in the general population,[31] thus may minimize the impact of  
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51 episodes of ill health and associated stressors for people aging with HIV. Similarly, productive  
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53 engagement in work and volunteering is also associated with successful aging.[32] These findings  
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reinforce the importance of promoting these strategies in people living with HIV through providing outlets to reciprocate social support and promoting strategies that facilitate positive cognitive coping.

For peer review only

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3 **Statements**

4

5 A. Contributorship statement

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7 PS and KKO developed the research question and designed the study. PS, KKO, RM and MS

8 participated in the data analysis. PS drafted the manuscript. KKO, RM and MS contributed to the

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12 critical revision and redrafting of the manuscript.

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17 B. Competing Interests

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19 None to declare.

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23 C. Funding

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32 D. Data Sharing Statement

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34 No additional data are available.

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# Standards for Reporting Qualitative Research (SRQR)\*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

## Title and abstract

<b>Title</b> - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1
<b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 2

## Introduction

<b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Pg 4 ln 2 – Pg 5 ln 16
<b>Purpose or research question</b> - Purpose of the study and specific objectives or questions	Pg 5 17-22

## Methods

<b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Pg 6 ln 2-3, 9-10
<b>Researcher characteristics and reflexivity</b> - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Pg 6, ln 20-21
<b>Context</b> - Setting/site and salient contextual factors; rationale**	Pg 6 ln 3-5
<b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Pg 6 ln 5-8
<b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Pg 7 ln 12-13
<b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Pg 6 ln 9-19



<b>Data collection instruments and technologies</b> - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Pg 6 ln 9, 21-22
<b>Units of study</b> - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Pg 7 ln 21 – Pg 8 ln 1
<b>Data processing</b> - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Pg 6 ln 21 – Pg 7 ln 6
<b>Data analysis</b> - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Pg 6, ln 22 – Pg 7 ln 3, Pg 7 ln 6-10
<b>Techniques to enhance trustworthiness</b> - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Pg 7 ln 3-11

Results/findings

<b>Synthesis and interpretation</b> - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pg 8 ln 4 – pg 14 ln 8
<b>Links to empirical data</b> - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Quotes throughout results section pgs 8 – 14

Discussion

<b>Integration with prior work, implications, transferability, and contribution(s) to the field</b> - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Pg 14 ln 11 – Pg 16 ln 20 Pg 17 ln 9 – Pg 18 ln 2
<b>Limitations</b> - Trustworthiness and limitations of findings	Pg 16 ln 21 – Pg 17 ln 8

Other

<b>Conflicts of interest</b> - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Pg 19 ln 7-8
<b>Funding</b> - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Pg 19 ln 10-12

\*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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\*\*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

**Reference:**

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014  
DOI: 10.1097/ACM.0000000000000388

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# BMJ Open

## A Longitudinal Qualitative Study on Living Strategies for Disability in Men Aging with HIV in Ontario, Canada

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Keywords:	HIV, episodic disability, longitudinal analysis, QUALITATIVE RESEARCH

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# **A Longitudinal Qualitative Study on Living Strategies for Disability in Men Aging with HIV in Ontario, Canada**

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Word Count: 4,535

## ABSTRACT

**Objectives:** To examine the living strategies used by older men living with HIV to deal with the episodic nature of disability and associated uncertainty, over time.

**Design:** Qualitative longitudinal study in which men living with HIV were interviewed on four occasions over 20 months.

**Setting:** Men were recruited from HIV community organizations in Canada.

**Participants:** 14 men with a median age of 57.5 years and median time since diagnosis of 21.5 years.

**Results:** Five themes depict the living strategies used to deal with the episodic nature of disability and uncertainty over time. Actively engaging in problem-solving by prioritizing and modifying activities and avoiding stress, advocating for support, being positive and future oriented, engaging in healthy pursuits and providing social support to others helped men to mitigate their disability. By following participants over time, we were able to gather insights into triggers of episodes of disability, and perceptions of the success of implementing their living strategies and avoiding uncertainty.

**Conclusions:** Participants used living strategies to deal with uncertainty and mitigate episodes of disability over time. This study supports the importance of programs that promote self-management for older men living with HIV through helping them identify triggers of disability, setting realistic goals and problem solving. These may help build self-efficacy, increase sense of control, and decrease feelings of uncertainty and episodes of disability.

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**STRENGTHS AND LIMITATIONS OF THIS STUDY**

- We conducted a longitudinal qualitative study of the living strategies used by older men living with HIV over time.
- We interviewed participants on 4 occasions over a 20-month time frame and achieved a 100% retention rate.
- Strengths included prolonged engagement participants over time and use of a disability lens as a foundation for this research.
- Limitations include an independent community-dwelling sample of long term survivors which may be better able to access supports and engage in positive living strategies.

## INTRODUCTION

In resource rich countries where people living with HIV are growing older and attaining a near normal life span, there has been increased recognition of HIV as a chronic illness that may result in health challenges, or disability.[1-4] In Canada, the prevalence of older adults ( $\geq 50$  years) living with HIV is increasing due to aging of long term survivors and an increase in new HIV diagnoses among this older age group.[5] Older adults living with HIV may experience disability related to the virus, side effects of medication, multimorbidity, and natural consequences of aging.[6] This disability may be compounded by significant social problems, stigma, mental health issues and social isolation.[7,8] Given this is the first cohort to grow old with HIV, it is important to understand the complexity of their disability.

The disability experienced by people living with HIV is often episodic in nature, associated with unpredictable fluctuating periods of good and ill health.[9] The Episodic Disability Framework, derived from people living with HIV, includes four dimensions of disability: symptoms and impairments, difficulties carrying out day to day activities, challenges to social inclusion and uncertainty that can be influenced by extrinsic and intrinsic contextual factors.[9]

While a key dimension in the Episodic Disability Framework, uncertainty resulting from unpredictable fluctuations in health is also viewed as a defining feature of aging with HIV that can increase anxiety of their everyday life.[10] Uncertainty is at the center of a model of disability influencing symptoms, activity and participation levels for older adults living with HIV.[11] Further modeling of dimensions of disability has suggested uncertainty is a direct and strong predictor of mental and emotional health challenges and challenges to social inclusion for people living with HIV.[12] Age-related uncertainties include worries about the source of health challenges, concerns about health providers' knowledge of HIV, financial and retirement concerns and long-term care and housing options.[13] Furlotte and Schwartz[14] reinforced that uncertainty contributes to mental distress among

1 older adults living with HIV. Kylmä et al[15] hypothesize that uncertainty can be both negative and  
2 positive; if combined with fear it may lead to hopelessness, while combined with wishing, is related to  
3 hope.

4 While a number of studies have reviewed how people living with HIV cope with a chronic  
5 illness,[16] few have addressed how they deal with the episodic nature of disability and associated  
6 uncertainty. Brashers et al[17] found that social support helped people living with HIV to manage  
7 uncertainty through a variety of strategies such as assisting with information seeking, providing  
8 instrumental support and offering acceptance. Uncertainties related to HIV are perceived differently by  
9 health professionals and people living with HIV, with professionals viewing uncertainty as related to a  
10 lack of scientific knowledge, and people living with HIV and policy makers viewing uncertainties as  
11 chronic stressors.[10]

12 In the Episodic Disability Framework, living strategies are intrinsic contextual factors that may  
13 interact and influence dimensions of disability including uncertainty.[9] The term living strategies was  
14 derived from the perspective of people living with HIV[9] and is analogous to coping in the context of  
15 HIV.[18] While there is some conceptual overlap, living strategies are differentiated from coping in that  
16 these can have both positive and negative influences on health.[18] A greater proportion of older adults  
17 with HIV engage in living strategies focused on maintaining a sense of control over one's health and  
18 adopt positive attitudes compared with younger adults with HIV.[18]

19 Studies examining coping and living strategies in older adults living with HIV have predominantly  
20 been cross-sectional in nature. Few have examined how the episodic nature of the disability, including  
21 the dimension of uncertainty, may be influenced by living strategies used by people living with HIV.  
22 Episodic disability is a temporal phenomenon best understood through longitudinal inquiry. Our goal  
23 was to answer the following research question: What is the nature and extent of living strategies used



1 by older adults living with HIV to manage the episodic nature of disability, and associated uncertainty,  
2 over time?

## 3 4 5 6 7 8 9 10 11 **METHODS**

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14 We conducted a longitudinal qualitative study involving a series of four, semi-structured face-to-  
15 face interviews with older men and women living with HIV. This was a part of a larger study of 24  
16 participants (14 who identified as men and 10 who identified as women). Each participant was engaged  
17 over a 20-month time frame. Interviews were scheduled 5 months apart to allow for changes in function  
18 and disability to occur but short enough to maintain momentum and promote retention.[19,20]

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21 Participants were recruited through HIV community organizations in Southern Ontario, through  
22 pamphlets onsite and recruitment notices on websites. Eligible participants were 50 years of age or  
23 older, who were diagnosed with HIV for more than 6 years. We excluded those newly diagnosed (< 6  
24 years ago) as this population may not have experienced ill health and/or disability associated with long  
25 term survival.[9,21] There are gender differences in the strategies people living with HIV use to deal with  
26 their health challenges.[22-24] Thus, in this study we present the analysis of the participants who  
27 identified as men.

28  
29 We used the Episodic Disability Framework[9] to guide the interviews. During the first interview  
30 (Time 1), we asked participants to provide a general description of their health challenges (or disability)  
31 including physical, cognitive, mental and emotional symptoms and impairments, difficulties carrying out  
32 day to day activities, uncertainty and challenges to social inclusion. The challenges were then explored  
33 in detail, probing for whether these were episodic in nature, and the living strategies used to address  
34 their health challenges. In subsequent interviews we explored the dimensions of disability identified in  
35 Time 1 and asked participants what changes occurred, how these occurred, and how these changes

1 affected their functioning and health. Our design allowed for emergent themes to be discussed over  
2 time. Participants received an honorarium at the completion of each interview. We collected  
3 demographic data at Time 1 and asked participants to complete the 20-item *HIV Symptom Index* which  
4 describes the number of symptoms present, and bothersome, to the individual.[25]

5 Analysis: All investigators contributed to the analyses. Interviews were audio-recorded,  
6 transcribed verbatim and entered into QDA Miner version 5 for data management.[26] Longitudinal  
7 qualitative analysis requires summary and comparison of data both longitudinally and cross-  
8 sectionally.[27] Initially, two investigators (RM and MS) independently carried out line by line coding of  
9 all four transcripts from one participant and developed a code book to guide our analysis.[28] The  
10 analysis focused on identifying disabilities, the living strategies used to deal with their challenges,  
11 triggers of episodes and whether the disability was episodic in nature (varied over the interviews).  
12 Codebook development was an iterative process involving ongoing discussion and revision. All  
13 transcripts from three participants were then reviewed independently with a subsequent meeting with a  
14 third investigator (PS) to refine the codebook and resolve discrepancies. The remaining transcripts were  
15 then each independently coded by two investigators (RM and MS) using the codebook. Verification of  
16 coding and themes was an iterative process discussed by all investigators at team meetings.[29] As we  
17 interviewed each participant on four occasions, we were able to follow the strategies used to address  
18 health challenges (or disability) and uncertainty over time. We developed an in-depth summary of each  
19 participant's disability experiences over time and compared these across participants to identify themes.  
20 All investigators reviewed and came to consensus on the final themes.

21 Research Ethics Board approvals were received from McMaster University and the University of  
22 Toronto. All participants provided written informed consent.

## 23 Patient and public involvement

This study is a part of a larger study in which a community member was included on the research team as one of the investigators. He reviewed and provided input on the research question and design prior to grant submission. Results of this study will be distributed to participants who indicated that they would like a copy of the research findings and provided contact information.

## RESULTS

Fourteen men volunteered to participate in this study and completed all four interviews. Participant age ranged from 50-73 years (median: 57.5 years; IQR 53.3-65.3) with a median time since diagnosis of 21.5 years (IQR 19.8-25). Demographic data are presented in Table 1. We identified five themes which illustrated the living strategies used by participants to manage uncertainty and minimize disability over time.

**Table 1. Participant Demographics**

Variable	n(%) or median (IQR)
Age (years)	57.5 (53.3-65.3)
Median Time since HIV diagnosis (years)	21.5 (19.8-25)
Sexual orientation	
Gay	12 (85.7)
Bisexual	1 (7.1)
Straight	1 (7.1)
Current marital/partnership status	
Single	9 (64.3)
Married/living together	4 (28.6)
Separated/divorced	1 (7.1)
Level of education	
High School or less	4 (28.6)
College diploma/University degree	7 (50)
Post-graduate education	2 (14.3)
Other	1 (7.1)
Estimated annual family income (CAD)	
≤\$30,000	10 (71.4)
\$40,000-\$70,000	2 (14.3)
>\$100,000	1 (7.1)
Missing	1 (7.1)
Employment status ( <i>multiple responses permitted</i> )	
Working full- or part-time	5 (35.7)
Unemployed	3 (21.4)
Volunteer	4 (28.6)
Retired	4 (28.6)
Student	1 (7.1)
HIV Symptom Index	
Total symptoms	10.5/20 (8-15)
Bothersome symptoms	10.5/20 (5.8-12)

Notes: n = 14; IQR: interquartile range

**Prioritizing Activities, Modifying Expectations, Avoiding Stress**

Participants described problem-solving and developing strategies to manage their disability. They experimented with many strategies over time and were able to evaluate the most successful options. Participants described cognitive strategies to avoid dwelling on uncertainty and worrying about the future, as stated by this participant,

...rather than worry about what might, what could (be)...(I am) just dealing with the thing when it comes up. I seem to be much better at not worrying about it or not getting depressed over it. (Participant 5, age 66; living with HIV (LWH) 20 years)

Participants described how they prioritized needs and activities, and set goals. For example, many were on a limited income and tried to proactively budget so that they were able to meet their nutritional and social needs. Participants stated how acceptance of their limitations helped to prioritize activities. For example, modification of tasks was a way to live with fatigue. This participant recognized his limitations and described how he felt it was possible to do activities he did when younger, "(if you change your strategy of how you accomplish it." (Participant 6, age 65; LWH 20 years).

Participants spoke of needing a "different approach" and adjusting their expectations of what they could accomplish. One participant described how he had stopped volunteering at a hospital because he found it exhausting, stating, "at this point I need to give more to myself than to others." (Participant 11, age 51; LWH 25 years).

Another participant described how letting "stuff" pile up could trigger depression and how he learned to decide whether he should engage in an activity:

I'm getting much better at doing (a cost-benefit analysis) and saying, okay, it's of more benefit for me to do it, even though it's going to be a little bit uncomfortable, than it's going to be not to do it... (Participant 5, age 66; LWH 20 years).

Often, a key to solving problems was the ability for participants to identify triggers of episodes of disability or ill health. Participants recognized stressors in their lives related to their illness, such as life and family situations which were triggers for mental health issues and could lead to activity limitations. Proactive stress avoidance was common. For example, participants described how they avoided individuals who did not contribute positively to their emotional well-being.

Through increased awareness of triggers of episodes of disability, many were able to prioritize activities, avoid uncertainty and mitigate an exacerbation. Weather was described as a trigger of depression and knowing this enabled participants to “deal with it”. Fatigue was a common experience and participants described how they needed to be “careful” to ensure that they had adequate energy levels. This participant described a 3-day regime to ensure he was rested and avoided depression.

(you can) roll around and relax and eat chocolates and feel sorry for yourself...but then after the third day you’ve got to get out of your environment whether it be your apartment or your head space and try to just go for a walk or do a bit of exercise.

(Participant 3, age 61; LWH 30 years)

### Self-Advocating for resources, care and support

The ability to advocate for resources, both medical and financial, was noted as a key strategy to manage challenges from disability. Participants described how remaining active and involved with their health provided a sense of control and stability which circumvented feelings of uncertainty. Participants reflected on how important it was to manage their health, with many taking an active role in learning about their medications and side effects, management strategies and co-morbidities. They negotiated around how often they would need to access the health system and their preferences for health providers. This participant described the role he preferred his family doctor to play in management of his overall health,

I’ll just talk to him next time I see him and say, ‘You’re my family doctor. I want you as my family doctor, you help me with a number of problems. But I don’t want you to be my HIV doctor. Period. I am the center of my care plan, not you.’ (Participant 1, age 73; LWH 21 years).

Participants sought out information to learn about their health from the internet, community HIV organizations and health providers to play a more active role in their management. Negotiating care around multiple providers was often challenging. One participant described how after a prostate cancer diagnosis he wanted to meet with the specialist and his family physician separately so that he could make the most informed decision about treatment options. Participants recognized that it was important to be organized for health care visits, which included coming prepared with questions as this participant stated, “(I) started questioning the doctors. What’s the medication going to do for me? What are the side effects?” (Participant 10, age 65; LWH 20 years)

Participants stated knowledge about their medications related to HIV management, pain management and other co-morbidities including diabetes. They advocated with their physicians about how to decrease their pill burden. One participant spoke at time 3 of wanting to be off all psychiatric medications and reported he had done so at time 4.

Participants also described how they advocated for supports and resources to improve health and quality of life for themselves and for their communities. Several lived in subsidized housing and described working with tenant associations to deal with adverse situations or negotiating for changes to improve housing. For example, this participant described how he advocated for smoke alarms in his apartment building,

I looked up the law and it says very clearly that the manager or whatever is responsible

for these things and I checked it out with the city. And I went down to our boss and said

I would be pleased to see us come to a compliance with the Ontario fire code.

(Participant 1, age 73; LWH 21 years)

## Looking to the Future with Positive Outlook

Participants described how their acceptance of aging with their illness allowed them to be positive and future-oriented. Although older, many contemplated returning to school or retraining for a new job. Participants planned on travelling, fixing up their apartments, starting to exercise and diet, and becoming involved in volunteering. Participants were pleased to be growing older and thought beyond their limitations and past disappointments. One participant was excited about a new romantic relationship as he thought this would not happen at his age; as he stated,

...I was shocked that he was calling to ask me to go out for dinner. I thought, you must be joking. This stuff doesn't happen to me. And I'm talking over a quarter of a century (since I've dated). So it's a long, long time. (Participant 6, age 56; LWH 20 years).

The longitudinal design of the study allowed us to observe some participants' plans and goals come to reality. One participant dreamed of going to New York to see the ballet and the opera and at the second interview stated he had achieved his goal. Another participant's goal of volunteering emerged as an opportunity to be on panel discussions and developing videos for health science students. One participant set a goal of getting a bicycle and was able to acquire one between the second and third interviews. Another planned to increase his walking and persisted "rain or shine".

Participants associated their positive outlook with acceptance of growing older as noted by this participant: "(I am) not thinking of aging, being old as an illness. It's simply a part of living." (Participant 1, age 73; LWH 21 years).

As long-term survivors with HIV, many participants reflected on their past challenges and contrasted this with their current status:

I think it's wonderful the medications that we have now, so that they can maintain a fairly substantial level of good health, for the long-term survivors. (Participant 6, age 65; LWH 20 years).



## Engaging in a Healthy Lifestyle

Twelve men described healthy lifestyle choices and expressed their desire to continue to live a healthy life as they aged with HIV. Many were committed to healthy pursuits as a way of coping with aging, HIV and comorbidity-related disability. Exercise and remaining physically active was the most common strategy articulated for maintaining health. With limited income, some found that walking was the most affordable exercise regime. As this participant stated, "I walk as much as I can. Public transit when I can but as little as possible" (Participant 5, age 66; LWH 20 years).

Many recognized when they needed external motivators to exercise regularly. Some joined the YMCA or a local gym. One participant started an outdoor walking program for older adults with cardiac problems. Another received a bicycle which "changed his life". One joined a fitness study which included the services of a fitness coach which he found very motivating. Several attributed improvements in their mood and musculoskeletal pain to regular exercise.

Diet and weight concerns were common. Participants linked exercise and diet as a weight loss strategy. Many had goals of losing weight and some succeeded over time. Participants sought dietician advice for co-morbidities such as diabetes and hypercholesteremia.

Other strategies for promoting a healthy lifestyle included learning to balance and pace activities to avoid fatigue. With increased activity several participants experienced more restorative sleep as noted by this participant: "(After going to the YMCA) I'm actually tired of doing something and I had a good sleep. And I actually sleep well. But when I didn't do the Y I wasn't sleeping properly". (Participant 4, age 54; LWH 25 years).

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**Valuing Reciprocity of Social Support**

Participants valued social support to help them deal with dimensions of disability (including uncertainty) and often sought to extend their circle of support. Support was received from many sources including family and friends, HIV community organizations, work and volunteer relationships, health and social services and virtual networks. HIV community organizations were described as the “main source” for support and as ways to access free activities (yoga class) or health and social services (nutritionist). Describing how he often felt depressed in the winter this participant stated, “But then as soon as I go to (the HIV community organization), everything changes.” (Participant 7, age 55; LWH 24 years).

Family members provided key supports, though several participants described dysfunctional family relationships over the duration of the study. Two participants stated that their support was “sufficient” and that they preferred being alone with one stating, “I like to be by myself.” (Participant 13, age 50; LWH 15 years).

The desire to also provide social support to others was an important aspect in the lives of many of the men. One participant described a complex relationship he had with an addicted homeless youth and how he tried to care for him. Another described how his family felt he was focusing too much on others and neglecting his own needs. When asked whether it was difficult to support others this participant remarked, “it takes your attention away from your own shtick.” (Participant 2, age 67; LWH 24 years).

As participants were older, some dealt with the complexities of providing support to aging parents. HIV community organizations provided a safe outlet for interaction and participants often volunteered to give back to their community. Several men participated in a “buddy program” through their local HIV community organization with one participant describing his role as a “friend counsellor”. Participants described how friends supported each other, “I still have a small cadre of friends that...we tend to interact when one of us gets sick.” (Participant 2, age 67; LWH 24 years).

Participants also experienced challenges seeking out social support, describing difficulty making new friends, especially someone in their “age bracket”. However, over time some developed new networks by joining organized activities such as a swimming group, seeking out walking “buddies” or by exercising at the YMCA. Some were reluctant to ask for practical support as stated by this participant,

I’ve learned, this was a hard one for me, I’ve learned to ask for help. My friends have all said to me that, you know, don’t be shy to say could you come over and give me a hand doing windows or something like that. (Participant 6, age 65; LWH 20 years).

## DISCUSSION

Overall this study portrays a positive picture of older men living with HIV who integrate living strategies into their lifestyle to address their disability over time. Actively engaging in problem-solving by prioritizing and modifying activities and avoiding stress, advocating for support, being positive and future oriented, engaging in healthy pursuits and providing social support to others helped men to mitigate their disability. Self-care and social support strategies were also found to be important in a cross-sectional Canadian study examining approaches to successful aging in people living with HIV.[30] By following participants over time, we gathered insights into triggers of episodes of disability and their perceptions of the success of implementing their living strategies and avoiding uncertainty.

While many studies of people living with HIV have identified the value of *receiving* social support, few have examined the benefits of *providing* social support. Our findings that men valued reciprocity of social support reinforces Emlet et al’s notion of generativity, or a sense of well-being for future generations, as a component of resilience or the successful adaptation to negative life events.[31] Participants in our study described reasons beyond “giving back” to the HIV community, including

1 pragmatic reasons such as caring for one's parents and as a way of diverting attention from their own  
2 problems.

3 Rosenfeld found that even people living with HIV with strong social support from those who are  
4 HIV negative require the mutual understanding that comes from individuals living with HIV and HIV  
5 community organizations.[32] The important role of HIV community organizations in facilitating links to  
6 social supports, and providing opportunities for adults aging with HIV to reciprocate their support to  
7 others, was reinforced in this study. Interestingly, avoidance of HIV support groups was identified as a  
8 strategy to support well-being by shifting the focus away from HIV.[32] This emphasizes the need for HIV  
9 community organizations to understand clients' needs and goals and tailor their support services  
10 accordingly.

11 Although a well-established approach for many chronic illnesses, self-management programs for  
12 people living with HIV are still emerging as a way to develop living strategies. This study supports the  
13 importance of programs that promote self-management for people living with HIV in several ways.  
14 Participants in this study learned to identify triggers of episodes of illness or disability to proactively  
15 mitigate severity of disability. This was important for setting realistic goals, a key component of self-  
16 management programs,[33] and for prioritizing and modifying their tasks and activities. Living strategies  
17 that include problem-solving can help build self-efficacy, increase one's sense of control and mitigate  
18 feelings of uncertainty.

19 The ability to communicate effectively with health providers and advocate for increased access  
20 to health services is another common component of self-management programs.[33] The participants  
21 were knowledgeable about HIV and the health system and described how they were able to advocate  
22 for their needs over time. Health literacy is important to be able to navigate the health system and  
23 knowledgeably express one's needs.[34] It is possible that many of the long-term survivors had to learn

1 to advocate for supports at a time when knowledge of HIV was emerging and stigma was widespread.  
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1 to advocate for supports at a time when knowledge of HIV was emerging and stigma was widespread.  
2 Regardless, increasing HIV knowledge and assisting people living with HIV with communicating their  
3 needs may be an important goal to enable better navigation of the health system for timely and  
4 appropriate access to resources.

5 The strategy of remaining future oriented with a positive outlook may be associated with  
6 resilience in those aging with HIV. Resilience may be a modifiable factor which is protective against  
7 cognitive and functional decline in people living with HIV.[35] Although further research is required to  
8 determine the causal relationship between resilience and function in people living with HIV, evidence  
9 suggests that interventions targeting resilience (e.g., positive reframing and coping) may be an  
10 important component of managing disability in older adults with HIV.[36] Self-efficacy is a protective  
11 factor which may moderate the negative consequences of living with HIV.[37] Self-management  
12 strategies that increase self-efficacy for dealing with the episodic nature of HIV and associated  
13 uncertainty, and promote positive coping, may help develop resilience living with HIV.

14 Although present, uncertainty did not play as prominent a role in participants' disability  
15 experiences, in contrast to other studies.[13] It is possible that the living strategies had been well-  
16 established and in use for some time by the men, and their attempts to pre-emptively identify triggers  
17 of disability helped them to avoid fluctuations in their health challenges and avoid uncertainty. People  
18 living with HIV also experience varied trajectories of episodic disability, one of which is described as  
19 stable.[38] Hence it is also possible that these participants experienced little fluctuation in their  
20 disability and less uncertainty over time.

21 Strengths of this study include the prolonged engagement and retention of all participants over  
22 the duration of this study which gave us insights into the living strategies used by people living with HIV  
23 over time. In addition, the use of a disability lens as a foundation for this research allows for

1 understandings into the consequences of comorbidities and how environmental and personal factors  
2 influence living strategies over time.

3 This study is limited in that participants were recruited from HIV community service  
4 organizations and thus may be a more independent community-dwelling sample better able to access  
5 supports and actively engage in positive living strategies. As time since diagnosis has been shown to be  
6 positively associated with resilience and mastery, an affective resource that helps develop self-  
7 control,[39] these long-term survivors may have been better able to cope with their episodic disability  
8 over time.

9 This research has several clinical implications. Self-management is recognized as an important  
10 element for developing long-term living strategies to manage chronic conditions, including HIV.[33]  
11 Increased access to health services and improved communication with health providers are common  
12 outcomes of self-management programs.[33] To achieve favorable health outcomes aging with HIV,  
13 people living with HIV require training and support to effectively self-manage their health, communicate  
14 their potential needs to access services, and participate in shared decision-making with their health care  
15 providers.

16 Participants did not link two of the living strategies, valuing reciprocity of social support and  
17 looking to the future, directly to dealing with the episodic nature of disability. It may be that these  
18 strategies are dispositional in nature and represent an overall approach to dealing with health  
19 challenges or disability. Being future oriented with a positive outlook assists in dealing with adversity  
20 and promotes successful aging in the general population,[40] thus may minimize the impact of episodes  
21 of ill health and associated stressors for people aging with HIV. Similarly, productive engagement in  
22 work and volunteering is also associated with successful aging.[41] These findings reinforce the

- 1 importance of promoting these strategies in people living with HIV through providing outlets to
- 2 reciprocate social support and promoting strategies that facilitate positive cognitive coping.

For peer review only

# 1 Statements

## 2 A. Contributorship statement

3 PS and KKO developed the research question and designed the study. PS, KKO, RM and MS  
4 participated in the data analysis. PS drafted the manuscript. KKO, RM and MS contributed to the  
5 critical revision and redrafting of the manuscript.

## 6 B. Competing Interests

7 None to declare.

## 8 C. Funding

9 This work was supported by the Canadian Institutes of Health Research (CIHR) under grant HHP  
10 131556. K.K. O'Brien is supported by a CIHR New Investigator Award.

## 11 D. Data Sharing Statement

12 No additional data are available.



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Standards for Reporting Qualitative Research (SRQR)\*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<b>Title</b> - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1
<b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 2

Introduction

<b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Pg 4 ln 2 – Pg 5 ln 18
<b>Purpose or research question</b> - Purpose of the study and specific objectives or questions	Pg 5 ln 19- Pg. 6 ln 2

Methods

<b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Pg 6 ln 5-8, 19
<b>Researcher characteristics and reflexivity</b> - Researchers’ characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers’ characteristics and the research questions, approach, methods, results, and/or transferability	Pg 7, ln 7-8
<b>Context</b> - Setting/site and salient contextual factors; rationale**	Pg 6 ln 12-14
<b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Pg 6 ln 14-18
<b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Pg 7 ln 23-24
<b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Pg 6 ln 19 – Pg 7 ln 6

<b>Data collection instruments and technologies</b> - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Pg 6 ln 19, Pg 7 ln 7-8
<b>Units of study</b> - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Pg 8 ln 8 – Pg 9 ln 2
<b>Data processing</b> - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Pg 7 ln 7-16
<b>Data analysis</b> - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Pg 7, ln 7-13, Pg 8 ln 16-22
<b>Techniques to enhance trustworthiness</b> - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Pg 7 ln 10-22

## Results/findings

<b>Synthesis and interpretation</b> - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pg 9 ln 4 – pg 16 ln 7
<b>Links to empirical data</b> - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Quotes throughout results section pgs 9 – 16

## Discussion

<b>Integration with prior work, implications, transferability, and contribution(s) to the field</b> - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Pg 19 ln 9 – Pg 18 ln 20 Pg 19 ln 9 – Pg 20 ln 2
<b>Limitations</b> - Trustworthiness and limitations of findings	Pg 19 ln 3-8

## Other

<b>Conflicts of interest</b> - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Pg 21 ln 7-8
<b>Funding</b> - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Pg 21 ln 10-12

\*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

\*\*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

**Reference:**

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014  
DOI: 10.1097/ACM.0000000000000388

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