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A Qualitative Longitudinal Study of Episodic Disability Experiences of Older Women Living with HIV

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ABSTRACT

Objectives To examine the episodic disability experiences of older women living with HIV over time.

Design Qualitative longitudinal study, conducting semi-structured in-depth interviews on four occasions over a 20-month time frame. Inductive thematic analyses were conducting cross-sectionally and longitudinally.

Setting Participants were recruited from community HIV organizations in Canada.

Participants Ten women 50 years of age or older living with HIV for greater than 6 years.

Results Two major themes related to the episodic nature of the women's disability. Women were living with multiple and complex sources of uncertainty over time including unpredictable health challenges, worrying about cognition, unreliable weather, fearing stigma and the effects of disclosure maintaining housing and adequate finances and fulfilling gendered and family roles. Women describe strategies to deal with uncertainty over time including withdrawing and limiting activities and participation and engaging in meaningful activities.

Conclusions The longitudinal study design highlighted the disabling effects of HIV in which unpredictable fluctuations in illness and health result in uncertainty and worrying about the future. Environmental factors such as stigma and weather may put older women living with HIV at a greater risk for social isolation. Strategies to promote dealing with uncertainty and building resilience are warranted.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- We conducted a longitudinal qualitative study of disability experienced by women living with HIV over the age of 50 years.
- We achieved a 100% retention rate of participants who were interviewed on four occasions over a 20-month time frame.
- We used a disability lens to understand the consequences of co-morbid health challenges and how the environmental context influences disability over time.
- This study did not include women diagnosed less than 6 years whose experiences may be very different from long term survivors.

INTRODUCTION

Advances in HIV management have led to an increased life expectancy approaching that of the general population for people living with HIV.[1] This increased longevity for those with access to anti-retroviral therapy has resulted in the recognition of HIV as a chronic illness often accompanied by disability.[2] Disability associated with HIV may be experienced as episodic in nature, characterized by unpredictable fluctuating periods of good and ill health.[3]

The *Episodic Disability Framework* was derived from the perspective of men and women living with HIV.[3,4] The Framework conceptualizes disability as the health-related consequences of HIV, adverse effects of treatments and concurrent health conditions that may fluctuate over time. The Framework spans physical, mental, emotional, and social life domains including four dimensions of disability: symptoms and impairments, difficulties with day-to-day activities, challenges to social inclusion, and uncertainty about future health that may be influenced by extrinsic (e.g., social support, stigma) and intrinsic (e.g., living strategies, gender and age) contextual factors.

Evidence suggests women living with HIV have unique physical, psychosocial and biological needs.[5] However knowledge of the nature and extent of the disability experienced specifically among older women living with HIV is unclear. Understanding gender specific disability has become more germane with the increasing number of adults over the age of 50 years and as women account for an increasingly higher proportion of adults aging with HIV in North America.[6]

Existing literature suggests that disability experienced by older women living with HIV affects self-care, coping, cognition and social participation. A gender analysis of older women aging with HIV revealed a complex model of social participation on a continuum from social isolation to social engagement.[7] Older African American women living with HIV find it more difficult to self-manage co-morbid conditions such as diabetes and hypertension.[8] Plach et al[9] conducted interviews with nine older women living with HIV and highlighted the importance for health providers to balance medical care with effective self-care. Psaoros et al[10] identified multiple sources of uncertainty in their qualitative study examining how 19 women over 50 coped with living with HIV. Difficulty accepting the uncertainty of the disease course was a key barrier in transitioning to a healthy coping style. A recent review on aging and neurocognitive functioning from literature involving a large cohort study in the US found that HIV positive women performed worse on measures of verbal learning and memory, however mean ages were in the mid-40's.[11] Hence, there is increasing importance to consider the multidimensional impact of disability experienced by women aging with HIV.

The majority of studies on gender related differences in older adults living with HIV were cross-sectional in design. While Plach et al[9] examined disability longitudinally, this study did not capitalize on the longitudinal design by offering insights on the disability process over time. It is important to understand how the fluctuating nature of the illness impacts on daily lives and disability experiences of older women living with HIV. As with aging, episodic disability is a temporal process and the consequences and contributions to disablement can only be illuminated through longitudinal study. Our aim was to examine the disability experiences of older women living with HIV over time.

METHODS

We conducted a longitudinal qualitative study involving a series of four semi-structured interviews with older 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 women 50 years of age or older, who were diagnosed with HIV more than 6 years ago.

We used the Episodic Disability Framework to guide the semi-structured interviews. During the first interview (Time 1), we asked participants to provide a general description of their health challenges including physical, cognitive, mental and emotional symptoms and impairments, difficulties carrying out day to day activities and challenges to social inclusion. The challenges were then explored in detail, probing for how the episodic nature, uncertainty and contextual factors affected the challenge. We explored participants' living strategies and social supports used to address their health challenges. To promote reflection on the episodic nature of HIV, in subsequent interviews we explored the health challenges identified in Time 1 and asked participants to consider what changes occurred, how these occurred, and how these changes affected their functioning, disability, and health. Our design allowed for emergent themes to be discussed over time. Thus, while specific challenges identified in previous interviews were explored in subsequent interviews, interviews enabled participants to identify new challenges that arose over time. Participants were provided with an honorarium at the completion of each interview.

Analysis: Interviews were audio-recorded, transcribed verbatim and entered into NVIVO 9[12] for data management. Longitudinal analysis requires summary and comparison of data both cross-sectionally and longitudinally. Our analysis involved four steps: Step 1) After the Time 1 interviews, two investigators (PS and NG) independently carried out line by line coding of three transcripts and developed a code book to guide our analysis.[13] The remaining Time 1 transcripts were then independently coded by two investigators from the research team using the code book. Using the coded transcripts at Time 1, we developed in depth *cross-sectional summary profiles for each participant*. Step 2) To examine the episodic nature of each participant's disability over time, we coded the data in a more structured way using the Episodic Disability Framework as a guide. Each investigator reviewed the Time 2 transcript of a participant and documented any changes (i.e., no change, improved or worsened) and/or new symptoms that emerged since Time 1 in areas consistent with categories in the Framework. We repeated this same process with the Time 3 and Time 4 transcripts for each participant. Step 3) We developed an in-depth summary of each participant's experiences over time. The end result of this step of the analysis was an *in-depth longitudinal summary profile that described the episodic nature of disability experienced by each participant over time.* The summary profiles for each participant were independently derived by two investigators and then amalgamated. Step 4) We compared the longitudinal summary profiles of participants to identify *thematic similarities and differences in the episodic nature of disability experiences among the participants over time.*

RESULTS

Ten women ranging from 51-61 years of age (median: 54 years; IQR= 52.25-58.75) participated in this study, all of whom completed 4 interviews over a 20 month period. Median time since diagnosis was 12.5 years (IQR=8-13.7). Three women reported being single, three were married or living with a partner and four were divorced. Five women received disability income support, three were working and two were seeking employment. Two women identified as visible minorities (Asian, African-Canadian) and one woman was indigenous Canadian.

We identified two major themes related to the episodic nature of participants' disability: I) Living with multiple and complex sources of uncertainty over time, and II) Strategies for dealing with episodic disability over time. Themes and sub-themes are summarized in Figure 1.

I Living with multiple and complex sources of uncertainty over time

Women were living with multiple, concurrent, evolving and overlapping sources of uncertainty which fluctuated over time. Some sources of uncertainty fluctuated minimally or remained stable over the period of the study. Women were managing complex and diverse fluctuations in their health challenges, co-morbidities and contextual factors which contributed to their uncertainty.

i) Unpredictable health challenges

All participants experienced fluctuations in their health challenges over the duration of the study. For many there were significant fluctuations in fatigue, insomnia, pain, mood and cognition. These fluctuations led to worries about whether they would have the capacity to fulfill their roles and responsibilities. For some the uncertainty was incapacitating and meant they could not plan for activities. Some described fluctuations on a day to day making it difficult to predict how much they could accomplish that day. This woman talked about the challenges of discerning a "good" day from a "bad" day: "…I can't tell a good day from a bad day when I wake up. It's just when I get someplace and it just becomes bad." (P9)

Other fluctuations occurred over weeks or even months. Unpredictability of these health fluctuations were highlighted over time. Often a new diagnosis or health challenge would arise at one of the interviews and be resolved by the next interview. For example, one woman faced a serious illness related to a urinary tract infection during interviews 2 and 3 which had resolved by interview 4.

The myriad health challenges experienced by the women led to worries about their health care and whether clinicians had the knowledge to deal with HIV-related issues. Some worried specifically about the knowledge related to women's needs.

> There's a lot of work to kind of being on top of [gynecological symptoms], and part of that is actually…educating and convincing doctors to pursue some of the tests that I think might be necessary. (P2)

For some, the ups and downs of their health challenges led to fears of getting seriously ill to the extent that they chose to remain home rather than interact with others. These fears were more evident during the winter months when there were increased probabilities of exposure to upper respiratory tract infections and influenza.

> Always when there are bugs going around, I literally hibernate in my home if I can. I carry Lysol in my car…seriously, I'll wear a mask shopping and stuff because…I am so paranoid. (P5)

ii) Worrying about cognition

Although many of the women were aware of normal age-related changes related to cognition and memory, often lapses in memory or concentration led to concerns about HIV-related dementia. Two women sought testing for cognitive impairments over the course of the study due to their worries; the results indicated normal cognitive aging. Two were diagnosed with HIV-related dementia and both lost their drivers' license, though one woman successfully appealed this during the course of the study. Some women accepted their cognitive decline and developed strategies such as note writing.

> Take your meds. Yeah, I have forgotten…I still forget what I'm going to do. I know a lot of people who…your attention…I got to go get something or whatever and by the time you get there I stand there and try and figure out what am I here for? (P9)

iii) Unreliable weather

The unpredictability of adverse winter weather was a concern for many women. Cold weather increased their pain, particularly joint and arthritic pain. Winter affected their mood and contributed to decreased energy and depression. Affordable activities, such as walking and cycling were curtailed by bad weather. Many felt "stressed" to be indoors and often felt an increased sense of isolation. One woman described herself as "hibernating" in the winter. Some did not venture outdoors due to a fear of falling. Women were aware of the effects of winter on their mood and levels of participation and dreaded its arrival. Some worried about curtailing their outdoor and social activities and becoming isolated, "There's not very much to do in the winter. I don't really go out much, so I just hate it." (P 8)

iv) Fearing stigma and the effects of disclosure

These women worried about stigma related to gender, age, race, HIV status and sexual orientation. Unemployment or precarious employment was often attributed to "being older", heterosexual, or a woman with perceptions that gay men or women of colour would get preference for coveted paid positions in HIV community organizations. Self-stigma related to

HIV was evident among all women including those who appeared to thrive and those working in HIV Community Organizations.

> I applied for a job here for my boss and I didn't get the job and somebody else has been in that job. Somebody else who is like a lot less qualified both educationally and experientially but, you know, he's a gay man. (P2)

Some women chose to limit their circle of disclosure due to a pervasive fear of stigma. Uncertainty related to whether people would associate with them if they revealed their HIV positive status. Some worried about accidental disclosure. One woman described how she felt she had to limit her associations with friends from a HIV Community Organization as she didn't know how she would explain these relationships to her family. Many women had not disclosed to immediate family members. These worries and concerns often increased social isolation or prohibited women from seeking supports from loved ones and friends.

> I'm very scared. I pick who I want to mix with because if I mix with people and they know my status, they won't want to mix with me. Believe me, that is the truth. People do not mix with people with HIV. (P1)

v) Maintaining housing and adequate finances

Maintaining housing and adequate finances were closely linked as housing was often the most significant living expense. The majority of women were in precarious employment, under-employed or on government disability pensions. Women worried about ageism affecting their employment status. Many women lived in supportive housing units, which over time became undesirable due to conflicts with neighbours and concerns about living conditions. Some women had not worked in many years and had given up on finding employment. Others worked in voluntary positions with HIV community organizations.

> So, I have anxieties…related to…the future…you know…financial concerns about not earning enough money, and so therefore, not having as much savings as I should, etc. etc. (P2).

vi) Fulfilling gendered and family roles

Over time, women faced uncertainty related to fulfilling gendered roles primarily related to caregiving and household responsibilities. As the women were older, their children were adults. Nonetheless, women valued their role as mother. One woman discussed how her children were living at home for the summer and how she was now cooking and doing their laundry. Another woman had to accommodate her daughter and two small grandchildren in her apartment after a failed relationship. Some women who were not permanently employed took on childcare responsibilities for extended family. Several women discussed the need to care for their aging parents.

> I was having problems with being a grandmother and not being the grandma that I wanted to be, you know, doing a good job and the responsibility of being a grandmother, you know? (P9)

II Dealing with uncertainty over time

The strategies that women used to navigate through the varied sources of uncertainty were revealed over time. While some women were overwhelmed and withdrew from activities and participation, others moved forward. Several women described a situation of isolation at the initial interviews but were able to make changes so that by the end of the study they described a life which was more engaged.

i) Withdrawing and limiting activities and participation

Some women's sense of being overwhelmed led them to withdraw from activities, becoming more socially isolated. This was particularly evident in women who were uncertain of the consequences of HIV disclosure. Rather than seeking support and sharing their challenges with others, they chose to limit whom they disclosed to and avoid others. One woman's social withdrawal was related to fears of getting ill. Some recognized the need for social support but were reluctant to "burden" family and friends. Other women were restricted by the winter weather further reinforcing their isolation.

> One of the reasons I was late this morning, my sister called me, I was almost going through the door and I couldn't tell her no because I didn't want to lie to her like, where are you going? Why can't you talk to me? And I sit and I had to talk to her for about 15 minutes. She wouldn't let go. I told her I got to go, I was telling her about something on sale today so she had the impression that I'm going to go get this thing that's on sale and didn't know I'm coming all the way here but I couldn't let her know. (P4)

ii) Engaging in meaningful activities

Some women sought activities that they felt contributed to their lives in meaningful ways. For a few this meant paid employment, though as noted this was often precarious in nature. The HIV Community Organizations provided an outlet for volunteer activities for many women; this had the added benefits of not having to worry about disclosure and providing access to support groups and education. Educating themselves about HIV led women to describe gaining a sense of control over their lives. The significant fluctuations in participation highlighted the relevance of the longitudinal inquiry; for example, one woman's life seemed hopeless at interviews 1 and 2; she was depressed, isolated and said she couldn't plan for the future. By interview 4 it appeared that she had turned her life around; she changed her way of interacting with her children and ex-husband, got a pet to provide some structure and meaning in her life and found a part-time job. As she stated "I've learned I have resilience". (P3)

The women who appeared to thrive over time tended to maintain a positive outlook, some through social comparisons with others. They developed a sense of purpose whether through caring for pets, family members or work activities. Many made lifestyle changes including watching their diet, being more physically active and quitting smoking. In contrast, some women felt unable to plan or look at the future and described living "day by day". A few, in spite of the uncertainties, were forward thinking and had goals and aspirations.

> I keep believing in my head I'm going to get a little bit better. I mean, maybe I won't get a whole lot better; I'm never obviously going to get back to what I was, you know, five years ago or whatever. (P10)

DISCUSSION

This study highlights the needs of older women living with HIV related to the episodic nature of disability and the associated uncertainty. The longitudinal study design allowed for a more nuanced understanding of uncertainty. In some instances the source of uncertainty was relatively stable over time (e.g., finances and housing) leading to chronic stressors. The episodic nature of chronic illness is increasingly recognized as an important characteristic impacting on disability.[14] Our study provided insights into the disabling effects of HIV in which unexpected fluctuations in illness and health resulted in uncertainty and worrying about the future. Uncertainty is a defining feature of older people living with HIV[15] and as a contributor to mental distress.[16] This study reinforces a model of disability of people aging with HIV which had uncertainty as the core affecting all components of disability including symptoms and impairments, difficulties in day to day activities and challenges to social participation.[17,18] By following the women over time, the complexities of managing multiple health challenges which fluctuated differentially is highlighted.

Strengths of this research include the prolonged engagement and retention of all participants over 20 months. In many instances, the participants were dealing with multiple fluctuating health and social issues which often affected their ability to participate and engage in their lives. If a single interview had occurred on a "good" or "bad" day the portrayal would be much different and the challenges of the episodic nature of the illness would not be evident. Other strengths are use of a disability lens as a foundation for this research which focused attention on the health *consequences* of the comorbidities, how physical and mental health diagnoses affect peoples' lives and how environmental and personal contextual factors interact with these over time. The longitudinal design of the study highlighted the uncertainty associated with the challenges of managing multiple symptoms, co-morbidities and complex lives. Given the potential consequences and the centrality of uncertainty in these women's lives, developing strategies to deal with stress and uncertainty in the overall management of people living with HIV is essential.

Limitations include our recruitment process through community HIV organizations, as participants who access these resources may represent a more engaged and mobile group with less disability. We also did not include women who were recently diagnosed with HIV, whose experiences may be very different to women who are longer term survivors and may be living with the long term consequences of chronic HIV inflammation, long term toxicity of older medications and having left the work force in the past prior to the advent of combination antiretroviral therapy. We also recognize that some sources of uncertainty experienced may be similarly experienced by men and younger women living with HIV. Additionally the 20-month time frame of the study may have been insufficient to see fluctuations in more stable sources of uncertainty such as housing and unemployment.

The women in our study experienced high levels of stress similarly reported by others.[11] Stress related factors may accelerate cognitive aging in people living with HIV.[11] Though many questions remain about the causal relationship, there is an association between anxiety and mild cognitive impairment in the general older population.[19] A multimodal integrative approach to the management of worry and anxiety, which includes exercise, mindfulness and cognitive training recommended for the general population,[19] is likely to be appropriate for a HIV population.

Current models of disability highlight the importance of the environmental context. Our longitudinal study followed the seasons over time and highlight how the uncertainty of weather impacted mobility and social participation of the participants. Weather is a risk factor for social isolation, health and well-being in the general older adult population,[20] but yet to be specifically considered in the context of HIV. Given that older people living with HIV are at increased risks for the deleterious effects of social isolation,[21] strategies to combat this are warranted.

Following participants over time revealed multiple forms of stigma experienced by women living with HIV and how it added to the complexity of uncertainty. Other gendered societal variables such as oppression and economic dependence may also contribute to maintaining stigmatizing attitudes.[5] Uncertainty related to the possible reactions from those who were disclosed to prevented some women from receiving necessary supports. Many of these concerns were not unfounded as women had experienced unwanted disclosure from health providers and alienation from their families. Older women's reluctance to disclose their status, even to family members, is of particular concern given their increased vulnerability for social isolation.[7,22] The perception that some people living with HIV receive preferential treatment due to varying characteristics (e.g., gender, ethnicity, age) speaks to the need for women to navigate self-stigma within the HIV community in addition to within their personal lives. HIV community organizations should consider the inclusiveness of programs to address stigma and provide opportunities for the diversity of people aging with HIV.

The diversity of the challenges experienced by these women highlights the importance of an interprofessional approach to HIV management. As HIV continues to evolve into a chronic illness, there is a need to include rehabilitation professionals who focus on client centered management of disability on the care team. Rehabilitation strategies promote self-management approaches which help to deal with uncertainty through building skills and promoting self-efficacy.[23] For example, occupational therapists can support women's personal, environmental and occupational needs through facilitating workplace participation, advocating for funding and assisting in navigating health care and political systems.[24] We agree that self-management programs need to be flexible and tailored to the individual needs of people living with HIV.[23,25] We also support the caution of Bernardin et al[23] that not all needs can be met through chronic disease self-management programs. Basic social determinants of health such as food and housing security may need to be met through concurrent programing.

Future research should include a quantitative examination of the synergistic and additive effects to further delineate the relationship between the episodic nature of disability and uncertainty in older women and men living with HIV. Additionally, in Canada indigenous populations are disproportionately affected by HIV and further exploration of their specific disability challenges are warranted. Ultimately the effectiveness of strategies to mitigate stress and uncertainty and minimize disability in older women living with HIV needs to be determined.

Statements

A. Contributorship statement

PS, KKO, SN and LL developed the research question and designed the study. PS, KKO, SN, LL, LB and NG participated in the data analysis. NG collected the data. PS drafted the manuscript. KKO, SN, LL, LB and NG contributed to the critical revision and redrafting of the manuscript.

B. Competing Interests

None to declare.

C. Funding

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D. Data Sharing Statement

No additional data are available.

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Figure Legend:

Themes and Sub-themes of Disability Experiences of Older Women Living with HIV Over Time

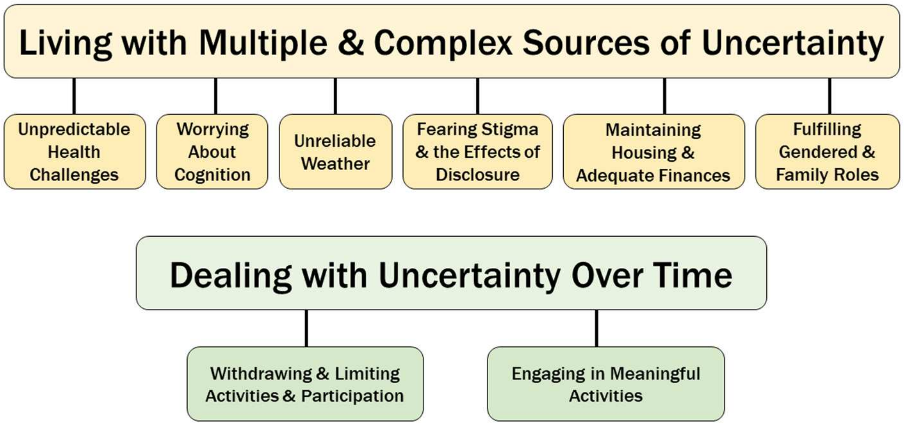

Figure 1. Themes and Sub-themes of Disability Experiences of Older Women Living with HIV Over Time

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ABSTRACT

Objectives To examine the episodic disability experiences of older women living with HIV over time.

Design Qualitative longitudinal study, conducting semi-structured in-depth interviews on four occasions over a 20-month time frame. Inductive thematic analyses were conducting cross-sectionally and longitudinally.

Setting Participants were recruited from community HIV organizations in Canada.

Participants Ten women 50 years of age or older living with HIV for greater than 6 years.

Results Two major themes related to the episodic nature of the women's disability. Women were living with multiple and complex sources of uncertainty over time including: unpredictable health challenges, worrying about cognition, unreliable weather, fearing stigma and the effects of disclosure, maintaining housing and adequate finances, and fulfilling gendered and family roles. Women describe strategies to deal with uncertainty over time including withdrawing and limiting activities and participation and engaging in meaningful activities.

Conclusions This longitudinal study highlighted the disabling effects of HIV over time in which unpredictable fluctuations in illness and health resulted in uncertainty and worrying about the future. Environmental factors such as stigma and weather may put older women living with HIV at a greater risk for social isolation. Strategies to promote dealing with uncertainty and building resilience are warranted.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- We conducted a longitudinal qualitative study of disability experienced by women living with HIV over the age of 50 years.
- We achieved a 100% retention rate of participants who were interviewed on four occasions over a 20-month time frame.
- We used a disability lens to understand the consequences of co-morbid health challenges and how the environmental context influences disability over time.
- This study did not include women diagnosed less than 6 years whose experiences may be very different from long term survivors.

INTRODUCTION

Advances in HIV management have led to an increased life expectancy approaching that of the general population for people living with HIV.[1] This increased longevity for those with access to anti-retroviral therapy has resulted in the recognition of HIV as a chronic illness often accompanied by disability.[2] Disability associated with HIV may be experienced as episodic in nature, characterized by unpredictable fluctuating periods of good and ill health.[3]

The *Episodic Disability Framework* was derived from the perspective of men and women living with HIV.[3,4] The Framework conceptualizes disability as the health-related consequences of HIV, adverse effects of treatments and concurrent health conditions that may fluctuate over time. The Framework spans physical, mental, emotional, and social life domains including four dimensions of disability: symptoms and impairments, difficulties with day-to-day activities, challenges to social inclusion, and uncertainty about future health that may be influenced by extrinsic (e.g., social support, stigma) and intrinsic (e.g., living strategies, gender and age) contextual factors.

Evidence suggests women living with HIV have unique physical, psychosocial and biological needs.[5] However knowledge of the nature and extent of the disability experienced specifically among older women living with HIV is unclear. Understanding gender specific disability has become more germane with the increasing number of adults over the age of 50 years and as women account for an increasingly higher proportion of adults aging with HIV in North America.[6]

Existing literature suggests that disability experienced by older women living with HIV affects self-care, coping, cognition and social participation. A gender analysis of older women aging with HIV revealed a complex model of social participation on a continuum from social isolation to social engagement.[7] Older African American women living with HIV find it more difficult to self-manage co-morbid conditions such as diabetes and hypertension.[8] Plach et al[9] conducted interviews with nine older women living with HIV and highlighted the importance for health providers to balance medical care with effective self-care. Psaoros et al[10] identified multiple sources of uncertainty in their qualitative study examining how 19 women over 50 coped with living with HIV. Difficulty accepting the uncertainty of the disease course was a key barrier in transitioning to a healthy coping style. A recent review on aging and neurocognitive functioning from literature involving a large cohort study in the US found that HIV positive women performed worse on measures of verbal learning and memory, however mean ages were in the mid-40's.[11] Hence, there is increasing importance to consider the multidimensional impact of disability experienced by women aging with HIV.

The majority of studies on gender related differences in older adults living with HIV were cross-sectional in design. While Plach et al[9] examined disability longitudinally, this study did not capitalize on the longitudinal design by offering insights on the disability process over time. It is important to understand how the fluctuating nature of the illness impacts on daily lives and disability experiences of older women living with HIV. As with aging, episodic disability is a temporal process and the consequences and contributions to disablement can only be illuminated through longitudinal study. Our aim was to examine the disability experiences of older women living with HIV over time.

METHODS

We conducted a longitudinal qualitative study involving a series of four semi-structured interviews with older 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 women 50 years of age or older, who were diagnosed with HIV more than 6 years ago. Due to the large amount of data generated through longitudinal interviews, our aim was to retain a sample of 10 women overtime (yield of 96 interviews).

We used the Episodic Disability Framework to guide the semi-structured interviews. During the first interview (Time 1), we asked participants to provide a general description of their health challenges including physical, cognitive, mental and emotional symptoms and impairments, difficulties carrying out day to day activities and challenges to social inclusion. The challenges were then explored in detail, probing for how the episodic nature, uncertainty and contextual factors affected the challenge. We explored participants' living strategies and social supports used to address their health challenges. To promote reflection on the episodic nature of HIV, in subsequent interviews we explored the health challenges identified in Time 1 and asked participants to consider what changes occurred, how these occurred, and how these changes affected their functioning, disability, and health. Our design allowed for emergent themes to be discussed over time. Thus, while specific challenges identified in previous interviews were explored in subsequent interviews, interviews enabled participants to identify new challenges that arose over time. Interviews were conducted by an investigator with experience in conducting qualitative interviews with vulnerable populations (NG). Participants were provided with an honorarium at the completion of each interview.

Analysis: All investigators contributed to the analyses. Investigators had complementary areas of expertise in gerontology, HIV, disability and personal experience growing older with HIV. Interviews were audio-recorded, transcribed verbatim and entered into NVIVO 9[12] for data management. Longitudinal analysis requires summary and comparison of data both cross-sectionally and longitudinally. Our analysis involved four steps: Step 1) After the Time 1 interviews, two investigators (PS and NG) independently carried out line by line coding of three transcripts and developed a code book to guide our analysis.[13] The remaining Time 1 transcripts were then independently coded by two investigators from the research team using the code book. Using the coded transcripts at Time 1, we developed in depth *cross-sectional summary profiles for each participant*. Step 2) To examine the episodic nature of each participant's disability over time, we coded the data in a more structured way using the Episodic Disability Framework as a guide. Each investigator reviewed the Time 2 transcript of a participant and documented any changes (i.e., no change, improved or worsened) and/or new symptoms that emerged since Time 1 in areas consistent with categories in the Framework. We repeated this same process with the Time 3 and Time 4 transcripts for each participant. Step 3) We developed an in-depth summary of each participant's experiences over time. The end result of this step of the analysis was an *in-depth longitudinal summary profile that described the episodic nature of disability experienced by each participant over time.* The summary profiles for each participant were independently derived by two investigators and then amalgamated. Step 4) We compared the longitudinal summary profiles of participants to identify *thematic similarities and differences in the episodic nature of disability experiences among the participants over time.*

This research was approved by Research Ethics Boards of McMaster University and University of Toronto. All participants provided informed consent.

Patient and Public Involvement

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 and was involved in the analysis and interpretation of the findings. 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

Ten women ranging from 51-61 years of age (median: 54 years; IQR= 52.25-58.75) participated in this study, all of whom completed 4 interviews over a 20 month period. Median time since diagnosis was 12.5 years (IQR=8-13.7). Three women reported being single, three were married or living with a partner and four were divorced. Five women received disability income support, three were working and two were seeking employment. Two women identified as visible minorities (Asian, African-Canadian) and one woman was indigenous Canadian.

We identified two major themes related to the episodic nature of participants' disability: I) Living with multiple and complex sources of uncertainty over time, and II) Strategies for dealing with episodic disability over time. Themes and sub-themes are summarized in Figure 1.

I Living with multiple and complex sources of uncertainty over time

Women were living with multiple, concurrent, evolving and overlapping sources of uncertainty which fluctuated over time. Some sources of uncertainty fluctuated minimally or remained stable over the period of the study. Women were managing complex and diverse fluctuations in their health challenges, co-morbidities and contextual factors which contributed to their uncertainty.

i) Unpredictable health challenges

All participants experienced fluctuations in their health challenges over the duration of the study. For many there were significant fluctuations in fatigue, insomnia, pain, mood and cognition. These fluctuations led to worries about whether they would have the capacity to fulfill their roles and responsibilities. For some the uncertainty was incapacitating and meant they could not plan for activities. Some described fluctuations on a day to day making it difficult to predict how much they could accomplish that day. This woman talked about the challenges of discerning a "good" day from a "bad" day: "…I can't tell a good day from a bad day when I wake up. It's just when I get someplace and it just becomes bad." (P9)

Other fluctuations occurred over weeks or even months. Unpredictability of these health fluctuations were highlighted over time. Often a new diagnosis or health challenge would arise at one of the interviews and be resolved by the next interview. For example, one woman faced a serious illness related to a urinary tract infection during interviews 2 and 3 which had resolved by interview 4.

The myriad health challenges experienced by the women led to worries about their health care and whether clinicians had the knowledge to deal with HIV-related issues. Some worried specifically about the knowledge related to women's needs.

> There's a lot of work to kind of being on top of [gynecological symptoms], and part of that is actually…educating and convincing doctors to pursue some of the tests that I think might be necessary. (P2)

The ups and downs of the women's health challenges led to fears of getting seriously ill to the extent that they chose to remain home rather than interact with others. These fears were more evident during the winter months when there were increased probabilities of exposure to upper respiratory tract infections and influenza.

> Always when there are bugs going around, I literally hibernate in my home if I can. I carry Lysol in my car…seriously, I'll wear a mask shopping and stuff because…I am so paranoid. (P5)

ii) Worrying about cognition

Although many of the women were aware of normal age-related changes related to cognition and memory, lapses in memory or concentration led to concerns about HIV-related dementia in six women. Two women sought testing for cognitive impairments over the course of the study due to their worries; the results indicated normal cognitive aging. Two were diagnosed with HIV-related dementia and both lost their drivers' license, though one woman successfully appealed this during the course of the study. Some women accepted their cognitive decline and developed strategies such as note writing.

> Take your meds. Yeah, I have forgotten…I still forget what I'm going to do. I know a lot of people who…your attention…I got to go get something or whatever and by the time you get there I stand there and try and figure out what am I here for? (P9)

iii) Unreliable weather

The unpredictability of adverse winter weather was a concern for seven of the women. Cold weather increased their pain, particularly joint and arthritic pain. Winter affected their mood and contributed to decreased energy and depression. Affordable activities, such as walking and cycling were curtailed by bad weather. Many felt “stressed” to be indoors and often felt an increased sense of isolation. One woman described herself as “hibernating” in the winter. Some did not venture outdoors due to a fear of falling. Women were aware of the effects of winter on their mood and levels of participation and dreaded its arrival. Some worried about curtailing their outdoor and social activities and becoming isolated, “There’s not very much to do in the winter. I don’t really go out much, so I just hate it.” (P 8)

iv) Fearing stigma and the effects of disclosure

These women worried about stigma related to gender, age, race, HIV status and sexual orientation. Unemployment or precarious employment was often attributed to “being older”, heterosexual, or a woman with perceptions that gay men or women of colour would get preference for coveted paid positions in HIV community organizations. Self-stigma related to HIV was evident among all women including those who appeared to thrive and those working in HIV Community Organizations.

> I applied for a job here for my boss and I didn’t get the job and somebody else has been in that job. Somebody else who is like a lot less qualified both educationally and experientially but, you know, he’s a gay man. (P2)

Six women chose to limit their circle of disclosure due to a pervasive fear of stigma. Uncertainty related to whether people would associate with them if they revealed their HIV positive status. Some worried about accidental disclosure. One woman described how she felt she had to limit her associations with friends from a HIV Community Organization as she didn’t know how she would explain these relationships to her family. Many women had not disclosed to immediate family members. These worries and concerns often increased social isolation or prohibited women from seeking supports from loved ones and friends.

> I'm very scared. I pick who I want to mix with because if I mix with people and they know my status, they won't want to mix with me. Believe me, that is the truth. People do not mix with people with HIV. (P1)

v) Maintaining housing and adequate finances

Nine women expressed financial and housing concerns. Maintaining housing and adequate finances were closely linked as housing was often the most significant living expense. The majority of women were in precarious employment, under-employed or on government disability pensions. Women worried about ageism affecting their employment status. Many women lived in supportive housing units, which over time became undesirable due to conflicts with neighbours and concerns about living conditions. Some women had not worked in many years and had given up on finding employment. Others worked in voluntary positions with HIV community organizations.

> So, I have anxieties…related to…the future…you know…financial concerns about not earning enough money, and so therefore, not having as much savings as I should, etc. etc. (P2).

vi) Fulfilling gendered and family roles

Over time, six women expressed uncertainty related to fulfilling gendered roles primarily related to caregiving and household responsibilities. As the women were older, their children were adults. Nonetheless, women valued their role as mother. One woman discussed how her children were living at home for the summer and how she was now cooking and doing their laundry. Another woman had to accommodate her daughter and two small grandchildren in her apartment after a failed relationship. Some women who were not permanently employed took on childcare responsibilities for extended family. Several women discussed the need to care for their aging parents.

> I was having problems with being a grandmother and not being the grandma that I wanted to be, you know, doing a good job and the responsibility of being a grandmother, you know? (P9)

II Dealing with uncertainty over time

The strategies that women used to navigate through the varied sources of uncertainty were revealed over time. While some women were overwhelmed and withdrew from activities and participation, others moved forward. Several women described a situation of isolation at the initial interviews but were able to make changes so that by the end of the study they described a life which was more engaged.

i) Withdrawing and limiting activities and participation

Five women's sense of being overwhelmed led them to withdraw from activities, becoming more socially isolated. This was particularly evident in women who were uncertain of the consequences of HIV disclosure. Rather than seeking support and sharing their challenges with others, they chose to limit whom they disclosed to and avoid others. One woman's social withdrawal was related to fears of getting ill. Some recognized the need for social support but were reluctant to "burden" family and friends. Other women were restricted by the winter weather further reinforcing their isolation.

> One of the reasons I was late this morning, my sister called me, I was almost going through the door and I couldn't tell her no because I didn't want to lie to her like, where are you going? Why can't you talk to me? And I sit and I had to talk to her for about 15 minutes. She wouldn't let go. I told her I got to go, I was telling her about something on sale today so she had the impression that I'm going to go get this thing that's on sale and didn't know I'm coming all the way here but I couldn't let her know. (P4)

ii) Engaging in meaningful activities

Five women sought activities that they felt contributed to their lives in meaningful ways. For a few this meant paid employment, though as noted this was often precarious in nature. The HIV Community Organizations provided an outlet for volunteer activities for many women; this had the added benefits of not having to worry about disclosure and providing access to support groups and education. Educating themselves about HIV led women to describe gaining a sense of control over their lives. The significant fluctuations in participation highlighted the relevance of the longitudinal inquiry; for example, one woman's life seemed hopeless at interviews 1 and 2; she was depressed, isolated and said she couldn't plan for the future. By interview 4 it appeared that she had turned her life around; she changed her way of interacting with her children and ex-husband, got a pet to provide some structure and meaning in her life and found a part-time job. As she stated "I've learned I have resilience". (P3)

The women who appeared to thrive over time tended to maintain a positive outlook, some through social comparisons with others. They developed a sense of purpose whether through caring for pets, family members or work activities. Many made lifestyle changes including watching their diet, being more physically active and quitting smoking. In contrast, some women felt unable to plan or look at the future and described living “day by day”. A few, in spite of the uncertainties, were forward thinking and had goals and aspirations.

> I keep believing in my head I’m going to get a little bit better. I mean, maybe I won’t get a whole lot better; I’m never obviously going to get back to what I was, you know, five years ago or whatever. (P10)

DISCUSSION

This study highlights the needs of older women living with HIV related to the episodic nature of disability and the associated uncertainty. The longitudinal study design allowed for a more nuanced understanding of uncertainty. In some instances the source of uncertainty was relatively stable over time (e.g., finances and housing) leading to chronic stressors. The episodic nature of chronic illness is increasingly recognized as an important characteristic impacting on disability.[14] Our study provided insights into the disabling effects of HIV in which unexpected fluctuations in illness and health resulted in uncertainty and worrying about the future. Uncertainty is a defining feature of older people living with HIV[15] and is a contributor to mental distress.[16] This study reinforces a model of disability of people aging with HIV which had uncertainty as the core affecting all components of disability including symptoms and impairments, difficulties in day to day activities and challenges to social participation.[17,18] By following the women over time, the complexities of managing multiple health challenges which fluctuated differentially is highlighted.

Strengths of this research include the prolonged engagement and retention of all participants over 20 months. In many instances, the participants were dealing with multiple fluctuating health and social issues which often affected their ability to participate and engage in their lives. If a single interview had occurred on a “good” or “bad” day the portrayal would be much different and the challenges of the episodic nature of the illness would not be evident. Other strengths are use of a disability lens as a foundation for this research which focused attention on the health *consequences* of the comorbidities, how physical and mental health diagnoses affect peoples’ lives and how environmental and personal contextual factors interact with these over time. The longitudinal design of the study highlighted the uncertainty associated with the challenges of managing multiple symptoms, co-morbidities and complex lives. Given the potential consequences and the centrality of uncertainty in these women’s lives, developing strategies to deal with stress and uncertainty in the overall management of people living with HIV is essential.

Limitations include our recruitment process through community HIV organizations, as participants who access these resources may represent a more engaged and mobile group with less disability. We also did not include women who were recently diagnosed with HIV, whose experiences may be very different to women who are longer term survivors and may be living with the long term consequences of chronic HIV inflammation, long term toxicity of older medications and having left the work force in the past prior to the advent of combination antiretroviral therapy. We also recognize that some sources of uncertainty experienced may be similarly experienced by men and younger women living with HIV. Additionally the 20-month time frame of the study may have been insufficient to see fluctuations in more stable sources of uncertainty such as housing and unemployment.

The women in our study experienced high levels of stress similarly reported by others.[11] Stress related factors may accelerate cognitive aging in people living with HIV.[11] Though many questions remain about the causal relationship, there is an association between anxiety and mild cognitive impairment in the general older population.[19] A multimodal integrative approach to the management of worry and anxiety, which includes exercise, mindfulness and cognitive training recommended for the general population,[19] is likely to be appropriate for a HIV population.

Current models of disability highlight the importance of the environmental context. Our longitudinal study followed the seasons over time and highlight how the uncertainty of weather impacted mobility and social participation of the participants. Weather is a risk factor for social isolation, health and well-being in the general older adult population,[20] but yet to be specifically considered in the context of HIV. Given that older people living with HIV are at increased risks for the deleterious effects of social isolation,[21] strategies to combat this are warranted.

Following participants over time revealed multiple forms of stigma experienced by women living with HIV and how it added to the complexity of uncertainty. Other gendered societal variables such as oppression and economic dependence may also contribute to maintaining stigmatizing attitudes.[5] Uncertainty related to the possible reactions from those who were disclosed to prevented some women from receiving necessary supports. Many of these concerns were not unfounded as women had experienced unwanted disclosure from health providers and alienation from their families. Older women's reluctance to disclose their status, even to family members, is of particular concern given their increased vulnerability for social isolation.[7,22] The perception that some people living with HIV receive preferential treatment due to varying characteristics (e.g., gender, ethnicity, age) speaks to the need for women to navigate self-stigma within the HIV community in addition to within their personal lives. HIV community organizations should consider the inclusiveness of programs to address stigma and provide opportunities for the diversity of people aging with HIV.

The diversity of the challenges experienced by these women highlights the importance of an interprofessional approach to HIV management. As HIV continues to evolve into a chronic illness, there is a need to include rehabilitation professionals who focus on client centered management of disability on the care team. Rehabilitation strategies promote self-management approaches which help to deal with uncertainty through building skills and promoting self-efficacy.[23] For example, occupational therapists can support women's personal, environmental and occupational needs through facilitating workplace participation, advocating for funding and assisting in navigating health care and political systems.[24] We agree that self-management programs need to be flexible and tailored to the individual needs of people living with HIV.[23,25] We also support the caution of Bernardin et al[23] that not all needs can be met through chronic disease self-management programs. Basic social determinants of health such as food and housing security may need to be met through concurrent programing.

Future research should include a quantitative examination of the synergistic and additive effects to further delineate the relationship between the episodic nature of disability and uncertainty in older women and men living with HIV. Additionally, in Canada indigenous populations are disproportionately affected by HIV and further exploration of their specific disability challenges are warranted. Ultimately the effectiveness of strategies to mitigate stress and uncertainty and minimize disability in older women living with HIV needs to be determined.

Statements

A. Contributorship statement

PS, KKO, SN and LL developed the research question and designed the study. NG collected the data. PS, KKO, SN, LL, LB and NG participated in the data analysis. PS drafted the manuscript. KKO, SN, LL, LB and NG contributed to the critical revision and redrafting of the manuscript.

B. Competing Interests

None to declare.

C. Funding

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D. Data Sharing Statement

No additional data are available.

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Figure Legend:

Themes and Sub-themes of Disability Experiences of Older Women Living with HIV Over Time

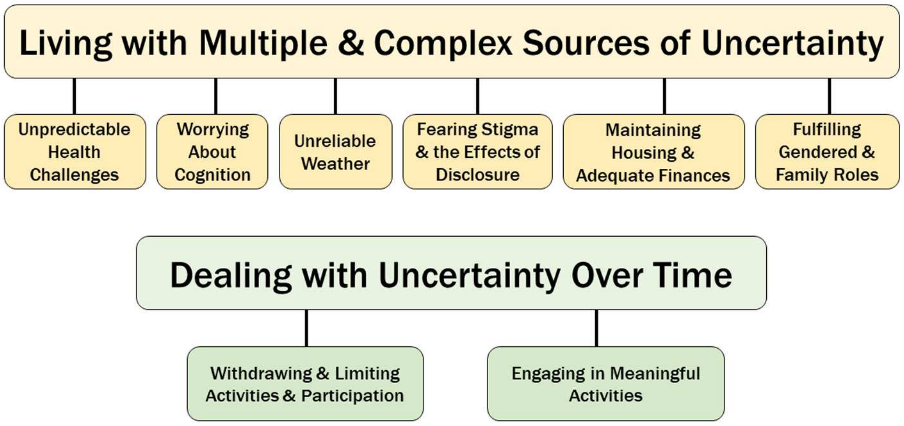

Figure 1. Themes and Sub-themes of Disability Experiences of Older Women Living with HIV Over Time

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Standards for Reporting Qualitative Research (SRQR)*

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Page/line no(s).

Title and abstract

Title - 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
Abstract - 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

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Pg 4 ln 38-54 Pg 5 ln 2-45
Purpose or research question - Purpose of the study and specific objectives or questions	Pg 5 40-47

Methods

Qualitative approach and research paradigm - 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 5 ln 51-53 Pg 6 ln 15
Researcher characteristics and reflexivity - 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 49-54
Context - Setting/site and salient contextual factors; rationale**	Pg 5 ln 52- pg 6 ln 6
Sampling strategy - 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 6-13
Ethical issues pertaining to human subjects - 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 47-50
Data collection methods - 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 15-45

Data collection instruments and technologies - 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 15-35
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Pg 8 5-17
Data processing - 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 54-pg 7 ln 3
Data analysis - 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**	Pg7 ln 3 - 45
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Pg 7 ln 6-15 Pg 7 ln 35-40

Results/findings

Synthesis and interpretation - 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 28 – pg 15 ln 9
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Quotes throughout results section pgs 8 – 15

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - 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 15 ln 13-41 Pg 16 ln 42- pg 18 ln 29
Limitations - Trustworthiness and limitations of findings	Pg 16 ln 19-40

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Pg 19 ln 19
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Pg 19 ln 25-29

*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
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