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Sensibility Assessment of the HIV Disability Questionnaire

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ABSTRACT

Purpose: Our purpose was to assess the sensibility of the Human Immunodeficiency Virus (HIV) Disability Questionnaire (HDQ), the first HIV-specific disability questionnaire.

Methods: We administered the HDQ, a sensibility questionnaire and a structured qualitative interview to 22 adults living with HIV and five experienced clinicians. We considered the HDQ sensible if median scores on the sensibility questionnaire were ≥ 5.0 for adults living with HIV and ≥ 4.0 for clinicians for at least 80% of the items. We analyzed the interview data using directed qualitative content analytical techniques.

Results: Questionnaire scores were ≥ 5 for 88% (15/17) of the items and ≥ 4 for 100% (17/17) of the items for adults living with HIV and clinicians, respectively. The interview analysis indicated participants felt the HDQ possessed face and content validity in all disability dimensions, had adequate response options, was easy to complete, and adequately captured the episodic nature of disability. Participants had mixed responses about the questionnaire title and provided recommendations to refine item wording and response options.

Conclusions: The HDQ appears sensible for use with adults living with HIV. Next steps include further measurement property assessment. The HDQ may be used by rehabilitation clinicians and researchers to assess disability experienced by adults living with HIV.

INTRODUCTION

Individuals living with Human Immunodeficiency Virus (HIV) infection can face health related challenges due to both the disease and potential side effects of treatment [1-5]. As people with HIV infection live longer, some individuals also may experience the premature onset of concurrent health conditions, such as bone and joint disorders, cardiovascular disease, and neurocognitive decline, resulting in additional health challenges [6, 7]. Together, these health related challenges may be termed *disability*.

In a previous study, we developed a conceptual framework of disability from the perspective of adults living with HIV infection, called the *Episodic Disability Framework*. This framework defines four dimensions of disability: symptoms and impairments; difficulties carrying out day-to-day activities; challenges to social inclusion; and uncertainty about future health that can fluctuate on a daily basis and over the course of living with HIV infection [8]. Furthermore, these dimensions can be exacerbated or alleviated by contextual factors which can be extrinsic (social support and stigma) or intrinsic (living strategies and personal attributes) [9].

Next, we developed a self-administered instrument, called the HIV Disability Questionnaire (HDQ) based upon the *Episodic Disability Framework* [10]. The HDQ is the first HIV-specific instrument to describe the presence, severity and episodic nature of disability experienced by adults living with HIV. The next steps in instrument development include assessing measurement properties, such as sensibility, validity, and reliability to ensure the HDQ is comprehensive, accurate and consistent for use with adults living with HIV. Sensibility specifically assesses whether an instrument is meaningful to respondents, described as “a mixture of ordinary common sense plus a reasonable knowledge of pathophysiology and clinical

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2
3 reality”[11]. We assessed the sensibility of the HDQ, including face and content validity and
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5 ease of use, for use with adults living with HIV [11].
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8 **METHODS**

9 **Study Design**

10 We used quantitative and qualitative methods to assess the sensibility of the HDQ from the
11
12 perspective of adults living with HIV and experienced clinicians who work in HIV care. We
13
14 collaborated with a Community Advisory Committee comprised of people living with HIV,
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16 members and employees of AIDS service organizations, and a representative of the Ontario
17
18 Ministry of Health and Long-Term Care throughout this study. This research was approved by
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20 Research Ethics Boards at McMaster University, Hamilton, Ontario and St. Michael’s Hospital,
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22 Toronto, Ontario, Canada.
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29 **HIV Disability Questionnaire (HDQ)**

30 The purpose of the HDQ is to describe the presence, severity and episodic nature of disability
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32 experienced by adults living with HIV. The 70-item self-administered questionnaire is
33
34 comprised of four domains: symptoms and impairments (35 items), uncertainty about future
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36 health (15 items), difficulties carrying out day-to-day activities (8 items), and challenges to
37
38 social inclusion (11 items) (table 1). Each item includes a statement about 1) a health-related
39
40 challenge asking how the respondent rates the challenge on the day of administration using a
41
42 seven point ordinal response scale and 2) a statement asking whether the challenge fluctuated
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44 (improved or worsened) over the past week using a nominal response scale. A final item asks
45
46 the respondent to classify his or her current health on the day of HDQ completion as either a
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48 ‘good day’ or ‘bad day’. Details of the HDQ development and scoring have been published
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50 elsewhere [10].
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[insert table 1 about here]

Sensibility Assessment

Evaluation of sensibility is often qualitative and frequently based on the judgment of clinicians and individuals for whom the questionnaire was developed [11]. We assessed components of Feinstein’s sensibility framework, which includes purpose and framework, overt format, face and content validity, and ease of use [11].

Participants and Recruitment

We included people living with HIV who were 18 years of age or older and self-identified as having experienced at least one health-related challenge attributed to their illness. Clinicians were from a range of health professions. We recruited HIV participants from two acute care hospitals, a specialty care hospital, and three community-based AIDS Service Organizations in Toronto and Hamilton, Ontario, Canada. We identified and recruited clinician participants through the Community Advisory Committee. Written informed consent was received from all participants.

Data Collection

We administered the HDQ, followed by a sensibility questionnaire that asked each participant to rate his or her level of agreement with 17 statements about face and content validity and ease of use of the HDQ using a seven point ordinal scale (see Appendix). Following the questionnaire administration, we conducted a structured interview asking participants whether the questionnaire adequately described their disability experience, whether it captured the episodic nature of disability over time, about the HDQ structure (e.g. adequacy of items and response options, readability, clarity of instructions, and overall format) and about ways to refine the HDQ to better capture the HIV-disability experience. Interviews were digitally recorded and

transcribed verbatim. Participants living with HIV also completed a demographic questionnaire and the HIV Symptom Index [12].

Analysis

HIV Disability Questionnaire: We calculated disability presence scores by summing the number of health challenges experienced (ranging from 0-69). We calculated disability severity scores by summing individual item scores from each domain and then linearly transforming them into four domain disability severity scores (ranging from 0 to 100). We divided the sum of these domain scores by four to obtain a total HDQ score (ranging from 0-100). Higher presence and severity scores indicated a greater presence and severity of disability.

We calculated a score reflecting the episodic nature of disability by summing the number of challenges identified as episodic in each domain and summing all four domain scores for a total episodic score (ranging from 0-69). We summed the number of participants who completed the HDQ on a 'good day' or 'bad day' living with HIV. We computed missing response rates for the disability, episodic, and health classification sections of the HDQ.

Sensibility Questionnaire: We calculated median scores for each of the 17 items in the questionnaire. We reverse scored 7 items so that higher scores indicated greater sensibility. We considered the HDQ sensible if median scores were ≥ 5 for adults living with HIV and ≥ 4 for clinicians who work in HIV care (seven point ordinal scale) for at least 80% of the items and if no items had median scores of ≤ 3 in either group. Rowe and Oxman used these criteria to determine sensibility of a quality of life instrument, weighting values slightly lower for clinicians based on the rationale that clinicians often require extensive evidence before accepting a new instrument [13].

Sensibility Interviews: We analyzed interview data using directed content analytical techniques [14]. We developed a coding scheme that addressed the following nine areas: overall impressions and purpose of the HDQ, face and content validity, ease of use, response options, overall format, ability to capture the episodic nature of disability and the questionnaire title. We used NVivo7 qualitative software for data management [15].

Theoretical saturation, constant comparative analysis, interviewer and analyst triangulation, and validity checks were used to enhance rigor [16-20]. Our approach allowed team members to share overall impressions of the interviews, cross-check the coding of the data, and refine the interview guide and coding scheme [21]. Four researchers independently coded half of the transcripts (multiple coding), and two researchers cross-checked codes for half of the merged transcript data. We formally reviewed consistency in coding, revisions to the interview guide, refinement of the coding scheme and analytical interpretations three times over the 12 month study. The Community Advisory Committee reviewed our preliminary findings and assisted with the interpretations of results.

RESULTS

We recruited 22 adults living with HIV (table 2) and five clinicians (one physician, two rehabilitation professionals, and one social worker) who work in HIV care between May and November 2009.

[insert table 2 about here]

HDQ Scores

The median number of health related challenges reported by adults living with HIV ranged from 8 of 11 (73%) in the social inclusion domain to 13 of 15 (87%) in the uncertainty domain (table 3). Median HDQ severity scores (scored from 0 to 100) were highest in the uncertainty domain

(52) followed by challenges to social inclusion (39), symptoms and impairments (35) and difficulties with day-to-day activities (28) (table 3). The number of challenges that fluctuated within the week was greatest in the symptoms and impairments domain with a median 12 of 35, followed by uncertainty (2 of 15), difficulties with day-to-day activities (1 of 8) and challenges to social inclusion (1 of 11) (table 3). Of the 22 participants living with HIV, 15 (68%) reported that they completed the HDQ on a 'good day', 4 (18%) on a 'bad day' and 3 (14%) did not answer the question. For the disability items in the HDQ, missing responses ranged from 0 to 18% and were highest in the challenges to social inclusion domain where four of 22 participants (18%) did not answer 'I have difficulty meeting the needs of those I am responsible caring for' and 'I feel a loss of community in relation to my HIV status'. For the episodic items, missing responses ranged from 0 to 36% where eight of 22 participants (36%) did not answer whether 'I have difficulty meeting the needs of those I am responsible caring for' fluctuated in the past week.

[insert table 3 about here]

Sensibility Questionnaire Scores

Adults living with HIV participants scored at least 5 (out of 7) on 15/17 items (88%) and at least 4 on all 17 items (100%) of the Sensibility Questionnaire. The two items that did not achieve ≥ 5 were 'the instrument included items that were repetitive or redundant' and 'there were items missing in this questionnaire that should be included'. HIV clinician participants scored at least 5 (out of 7) on 13/17 items (76%) and at least 4 on all 17 items (100%) of the Sensibility Questionnaire. Neither group had any items with median scores ≤ 3 .

Sensibility Interviews

Impressions and Purpose of the HDQ

Overall, participants had positive impressions of the HDQ describing the questionnaire as “thorough” and comprehensive. Participants felt the HDQ could be useful to clinicians, community-based AIDS service organizations and individuals living with HIV (table 4). Respondents thought the HDQ could provide a description of a “general idea of what a person's day is like” (INT-18) and the current health related challenges a person might experience (table 4). Respondents also said that the HDQ might describe the episodic nature in which health challenges may be experienced: the HDQ “[can be used] to identify if somebody is going through an episodic disability” (INT-13).

Face Validity

The HDQ demonstrated face validity in all four dimensions (table 4). In particular, participants highlighted the importance of the challenges to social inclusion and uncertainty domains: “the social inclusion, the uncertainty. That was the part that really stood out for me.” (INT-4) (table 4). Participants living with HIV felt the HDQ could be improved by asking “more detailed questions” (INT-17). Participants didn’t “think [the questionnaire is] going into enough depth” and commented on how they “would like to be able to express more... maybe say a little bit more of the why” (INT-18). Some participants wanted the opportunity to comment on the potential sources of health-related challenges experienced.

Content validity

Content validity was demonstrated in all four domains of the HDQ (table 4). Participants specifically highlighted 35 items (out of 69) that were important and essential to retain in the HDQ and did not identify any items unimportant to disability that could be excluded. Participants also indicated items that were missing and should be added to the HDQ (e.g. housing).

Ease of use

Participants found that the HDQ instructions and items were clearly written in ‘layman’s terms’ and at a literacy level that enabled participants to complete the questionnaire independently.

Overall, participants did not report any discomfort completing the HDQ (table 4). However, one participant highlighted how reading the HDQ was a reminder of his HIV status and the potential for episodes of disability independent of whether he experienced the challenges presently: “*it was a challenge...the question’s a reminder that I’m living with HIV every single day*” (INT-16).

Participants highlighted the importance for those administering the questionnaire to ensure they follow-up after the HDQ completion ‘*maybe an extra five minutes just to see how the person is feeling after the questionnaire and how they found the questionnaire.*’ (INT-14)

Participants completed the HDQ in approximately 15-20 minutes. Many felt the amount of time was feasible to complete the questionnaire and would be willing to complete the HDQ prior to a clinic appointment.

Response Options

Overall, participants found the seven point ordinal response scale adequate for capturing disability presence and severity for each item (table 4). The response options for the episodic component of the questionnaire included ‘yes’ ‘no’ and ‘don’t know’. Sixty-eight out of 69 episodic items had either a missing or ‘don’t know’ response. The median number of missing and don’t know responses for each item were 2 (range: 0-8) and 2 (range: 0-3), respectively. One participant queried whether it might be important to specifically indicate whether a health-related challenge ‘improved’ versus ‘worsened’ over the past week. Some participants were confused as to whether they needed to complete the episodic component of each item if they did not experience a given challenge.

Format

Overall the format of the HDQ appeared clear (table 4). Items in the symptoms and impairments and difficulties with day-to-day activities domain were generic whereas items in the uncertainty and social inclusion domains were primarily HIV-specific, meaning the items asked about a given challenge ‘living with HIV’. Participants acknowledged that the items were negatively phrased such as: ‘I have difficulty with’; ‘I have problems’; or ‘I worry about’ to align with the purpose of the HDQ, to report on disability (or health-related challenges) experienced by adults living with HIV. Also, participants positively commented on the use of first person (“I”) throughout all items in the questionnaire (table 4).

Episodic component of the HDQ

Overall participants felt that the HDQ adequately captured the daily episodic nature of disability (table 4). Participants had mixed feelings whether the episodic timeframe should be 1 week; 2 weeks; 1 month; or 3-6 months to align with their clinic appointments. As one participant stated: “I think probably a week is good, cause if you get into any longer than that, you’re going to be faced with not remembering.” (INT-20)

Title of the HDQ

Participants had mixed responses about the term ‘disability’ in the questionnaire title (table 4). Clinicians, particularly rehabilitation professional participants, supported the title: HIV Disability Questionnaire. In particular, one clinician participant felt it was important to retain the term ‘disability’ because it clearly and accurately reflected the concept of interest as previously defined by adults living with HIV (table 4).

[insert table 4 about here]

DISCUSSION

Our study demonstrated that the HDQ possessed sensibility for measuring disability among adults living with HIV, specifically face and content validity and ease of use in all four domains as well as describing the daily episodic nature of disability. While quality of life measures are widely documented in the HIV literature [22-26] the HDQ is the first HIV-specific instrument to describe the presence, severity and episodic nature of disability. Our study also highlighted several areas for future revision.

Items in the symptoms and impairments and difficulties with day-to-day activities domains were generic whereas items in the uncertainty and social inclusion domains were predominantly HIV-specific. The increasing prevalence of multiple morbidities associated with HIV and aging can make it difficult for individuals to distinguish between health related challenges attributed to HIV, side effects of medications, or concurrent health conditions [1, 27]. Consequently, the HDQ instructions did not ask individuals to distinguish between challenges attributed to HIV or other health conditions. However, important aspects of uncertainty or social exclusion related to HIV such as items related to criminalization of HIV transmission, disclosure of HIV status, and stigma associated with HIV-positivity should remain HIV-specific to adequately capture the breadth of health challenges experienced by adults living with HIV.

Uncertainty is a new dimension of disability and a key domain of the HDQ. Although uncertainty is a well recognized source of emotional distress, fear, anxiety, and depression for people living with HIV [28, 29], and associated with long-term survival [30], it was not included in HIV-specific health status questionnaires we reviewed before developing the HDQ [31]. Generic measures of uncertainty developed prior to the advent of combination antiretroviral therapy [32] likely do not reflect the unique aspects of uncertainty associated with living with

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HIV and the long term consequences of treatment. The high median presence (13 out of 15 challenges: 87%) and severity (52 out of 100) domain scores highlight the importance of uncertainty as a dimension of disability.

Participants highlighted items essential to retain in the HDQ, generated new items, and suggested revisions to enhance readability and applicability of items, but did not indicate any items we could exclude that were unimportant to disability. Participants felt 15-20 minutes was feasible to complete the HDQ, however respondent burden will increase if researchers administer this instrument with other measures in clinical research. Future HDQ revision should include ways to comprehensively measure disability with the fewest number of items to minimize respondent burden. In the next stages of HDQ development we will conduct a factor analysis of item scores with a larger sample of adults living with HIV to statistically identify any redundant items that can be removed [33].

The HDQ successfully captured the daily episodic nature of disability. Despite differences in opinion on the optimal timeframe for this question, assessing daily episodes within the previous week appears appropriate as participants might not accurately be able to recall fluctuations related to their health beyond seven days [34]. Episodic scores were higher for symptoms and impairments (e.g. fatigue, pain, headaches) in comparison to challenges to social inclusion (e.g. ability to work, relationships), which are less likely to fluctuate on a daily basis. Future research should explore how repeated administration of the HDQ over time can be used to document the degree of episodic disability and impact of major or momentous events such as opportunistic infections on disability.

Although participants felt the HDQ could be used by clinicians and community-based service organizations, measurement properties for uses with individuals in clinical or community

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3 practice have higher more stringent criteria compared with those used in clinical research and
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5 remains a topic for future research [35].
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8 Some participants were confused by the title, given the term ‘disability’ is prominently
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10 used in the HIV program and policy context related to employment and income support.
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12 Nevertheless, many participants understood the term as defined in the questionnaire instructions
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14 and felt it was important to retain the word ‘disability’ in the title to accurately reflect the HDQ
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16 purpose. This reasoning is consistent with the decision to retain ‘disability’ in the title of the
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18 *Episodic Disability Framework* [8] and this terminology is similarly used by rehabilitation
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20 professionals who work in HIV care [36].
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24 Several questions had high levels of missing responses, indicating candidate items for
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26 revision. Missing responses were highest for items in the challenges to social inclusion domain.
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28 Participants’ suggestions for providing ‘not applicable’ response options could reduce missing
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30 responses on these few items in future HDQ administration. In addition, high rates of missing
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32 and ‘don’t know’ responses on the episodic items highlighted potential confusion about whether
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34 participants needed to complete the episodic component of each item if they did not have the
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36 health related challenge. Given a one week timeframe enables recall of fluctuations in health
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38 challenges we will remove the ‘don’t know’ response option in the next revision. Clarifying
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40 instructions about completing the episodic component for each challenge and refining item
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42 wording and response options are needed to ease interpretability which may help to reduce
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44 missing responses and more accurately describe disability.
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50 The Sensibility Questionnaire has not been validated but is similar to previous sensibility
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52 assessments and based on an established framework [13]. As in previous sensibility research on
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54 a quality of life questionnaire, patients tended to provide higher sensibility ratings than clinicians
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for clarity and simplicity, item redundancy, response options and acceptability of the questionnaire [13]. Another limitation of our study is that most participants appeared ‘healthy’ meaning most rated their health status as excellent or very good, and the majority completed the HDQ on a ‘good day’. Longitudinal administration of the HDQ is needed to determine whether HDQ scores change within individuals who complete the questionnaire on ‘good days’ and ‘bad days’. Future validity and reliability testing should include broader administration of the HDQ to adults living with HIV with varying health and personal characteristics such as ethnocultural background, age, and gender, to ensure variability in scores and that the HDQ will be applicable for use across the HIV community [23]. Lastly, our goal was to assess sensibility (not measure disability) so HDQ scores should be interpreted cautiously given the small sample size and large proportion of missing responses. Next steps will include HDQ reliability and validity assessment with a larger sample of adults living with HIV.

CONCLUSION

The HDQ appears sensible for use with adults living with HIV, possessing face and content validity and ease of use in all four domains and describing the daily episodic nature of disability. Results highlight considerations for future revisions of HDQ item wording, content, terminology, response options, title and format, and administration and use of the HDQ with adults living with HIV. The HDQ may be used by rehabilitation clinicians and researchers to assess disability experienced by adults living with HIV.

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DECLARATION OF INTEREST

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Appendix – Adults Living with HIV - Sensibility Questionnaire

You have just completed the HIV Disability Questionnaire. The goal of the questionnaire is to describe disability experienced by adults living with HIV. We would like to get your feedback on its use. Please circle the most appropriate numeric answer on the scale in response to each of the following statements pertaining to the HIV Disability Questionnaire.

Face Validity

1. I was able to answer all of the questions.

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Highly Disagree

Disagree

Agree

Highly Agree

2. The instructions were clear and easy to understand.

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Highly Disagree

Disagree

Agree

Highly Agree

3. The questions were clear and easy to understand.

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Highly Disagree

Disagree

Agree

Highly Agree

4. The overall questionnaire makes sense.

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Highly Disagree

Disagree

Agree

Highly Agree

5. The response categories for the questions were adequate.

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Highly Disagree

Disagree

Agree

Highly Agree

Content Validity

6. The HIV Disability Questionnaire was intended to capture disability which has been defined by adults living with HIV as: symptoms and impairments, difficulties with day-to-day activities, challenges to social inclusion and uncertainty. The questionnaire captured all elements of my disability.

7. The instrument included important items that are necessary to describe my disability.

8. The instrument included items that were repetitive or redundant.*

9. There were items missing in this questionnaire that should be included.*

10. Some of the questions seemed out of order.*

11. I was able to find my answer in the list of possible answers to the questions.

Ease of Usage

12. I felt uncomfortable answering some of the questions because I did not want to have anyone know my answer.*

13. I felt that the questions made me think about things that I would have preferred not to have thought about.*

14. I felt that answering the questions helped me in some way.

15. The questionnaire took too long for me to complete.*

16. The survey required too much effort to complete.*

17. This questionnaire is useful in describing disability experienced by adults living with HIV.

*items reversed scored.

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Table 1: HIV Disability Questionnaire Items (Version 1)

HIV Disability Questionnaire Items	
Symptoms and Impairments (35 items)	
1. I feel too tired to do my usual activities.	
2. I have diarrhea	
3. I feel nauseous	
4. I have headaches	
5. I have numbness or tingling in my hands	
6. I have numbness or tingling in my feet	
7. I have aches or pains	
8. I have difficulty swallowing food	
9. I have decreased interest in having sex (decreased libido)	
10. I experience shortness of breath	
11. I am unsteady on my feet	
12. I experience fever, chills or sweats	
13. I feel weakness in my muscles	
14. I have muscle or stomach cramps	
15. I am experiencing weight loss or a decrease in my body composition	
16. I am experiencing weight gain or an increase in my body composition	
17. I have a lack of appetite	
18. I have difficulty sleeping	
19. I have difficulty remembering things	
20. I have difficulty thinking clearly	
21. I have difficulty concentrating	
22. I have problems with my vision	
23. I have problems with my hearing	
24. I feel dizzy	
25. I feel anxious or worried	
26. I feel sad, down or depressed	
27. I am fearful of my future living with HIV	
28. I feel a lack of confidence around others	
29. I am uncomfortable with the appearance of my body living with HIV	
30. I feel alienated by those around me (OR I feel that I don't belong) (OR I feel isolated even when I'm around others)	
31. I feel embarrassed around others due to my illness	
32. I feel a sense of guilt in relation to my illness	
33. I feel lonely living with my illness	
34. I feel discouraged about my future life options living with HIV	
35. I do not feel accepted by my friends and family	
Uncertainty (15 items)	
36. I worry about my future health living with HIV	
37. I worry about my numbers (CD4 count and viral load) with HIV	
38. I worry about having a serious illness living with HIV	
39. I worry about when my next even of illness might be living with HIV	
40. I worry about what the outcome of my next episode of illness might be living with HIV	
41. I worry about the side effects of HIV treatments	
42. I worry about my income or financial security living with HIV	
43. I worry what might happen to my family and friends if I have an episode of illness with HIV	
44. I worry about my ability to remain in the workforce or return to the workforce	
45. I worry about dying	

46. I worry about my bodily appearance living with HIV
47. I worry about the legal issues of telling others about my HIV status
48. I am worried about what others such as family and friends might think of me if they knew I was HIV positive
49. I worry about transmitting HIV to others
50. I have put certain life decisions on hold (such as buying a house, returning to work or school, or starting a family) because of my uncertainty living with HIV
Difficulties Carrying out Day-to-Day Activities (8 items)
51. I have difficulty walking
52. I have difficulty climbing stairs
53. I have difficulty carrying out daily activities such as eating, bathing, hygiene and dressing
54. I have difficulty carrying out household chores such as cleaning, doing dishes, laundry and cooking
55. I have difficulty carrying out leisure or recreational activities, such as exercise, dancing
56. I have difficulty getting out to do errand such as grocery shopping, getting to the bank or attending doctor's appointments
57. I have difficulty keeping track of my finances
58. I have difficulty getting around (either driving or taking public transportation)
Challenges to Social Inclusion (11 items)
59. I have difficulty meeting the needs of those I am responsible caring for (i.e. children, parents, grandparents, and partners)
60. I have difficulty fulfilling my role as a family or community members living with HIV
61. I feel a loss of community in relation to my HIV status
62. My ability to work (either volunteer or paid work) or attend school is limited because of my illness
63. I feel that my performance in the workforce is hindered because of my illness
64. I have difficulty talking with others about my illness, including my family, children, or friends
65. I have difficulty asking others for assistance when I am experiencing an episode of illness
66. I have difficulty initiating new friendships
67. I have difficulty initiating new intimate or sexual relationships
68. I tend to isolate myself from others because I am HIV positive
69. I have difficulty taking part in recreational or leisure activities due to my illness
Health Classification (1 item)
70. Individuals living with HIV sometimes refer to having 'good days' and 'bad days' that refer to the fluctuating ups and downs or periods of wellness and illness. How would you classify your overall health today living with HIV?

Table 2: Characteristics of Participants Living with HIV (n=22)

Characteristic	Number (%)
<i>Gender</i>	
Male	12 (54%)
Female	9 (41%)
Transgendered	1 (<5%)
Median Age (years)	44 (range: 25-60 years)
Identified with particular ethnic group	12 (54%)
Nadir CD4 count <200 cells/mm ³	10 (45%)
Undetectable viral load	14 (64%)
Diagnosed Prior to 1996	9 (41%)
Median Number of Years Since HIV Diagnosis	13 (range: 1-25)
Currently Taking HIV Medications	17 (77%)
Currently Working	6 (27%)
Living Alone	12 (54%)
Have children	11 (50%) (range: expecting – 38 years)
<i>Self Rated Health Status</i>	
Excellent	2 (9%)
Very Good	9 (41%)
Good	6 (27%)
Fair	4 (18%)
Poor	1 (5%)
<i>HIV Symptom Index</i>	
Median Number of Symptoms Present	15/20 (IQR: 10-19)
Median Number of Bothersome Symptoms	13/20 (IQR: 10-18)^

^ Most bothersome symptoms included fatigue or loss of energy, feeling sad, down or depressed, changes in way body looks, feeling nervous or anxious, and muscles aches or joint pain.

IQR=interquartile range.

Table 3: HIV Disability Questionnaire Scores of Participants Living with HIV (n=22)

Disability Domain	Median presence score (number of challenges present (%))	Median severity score (range 0-100) (IQR)	Median episodic score (number of challenges that fluctuated in the past week (%))
Symptoms and Impairments (35 items)	26 (74%)	35 (27-42)	12 (34%)
Uncertainty (15 items)	13 (87%)	52 (32-62)	2 (13%)
Difficulties Carrying out Day-to-Day Activities (8 items)	6 (75%)	28 (17-52)	1 (12%)
Challenges to Social Inclusion (11 items)	8 (73%)	39 (23-50)	1 (9%)
Total (69 items)	50 (73%)	39 (23-49)	21 (30%)

IQR=interquartile range; values rounded to nearest whole number; higher scores indicate higher presence, severity and daily episodic nature of disability

Table 4: Sensibility Assessment from Interviews**Overall Impressions of the HDQ**

Overall participants had positive impressions of the HDQ:

“extensive... well put together... covered a large range of the conditions that somebody like myself that’s been fourteen years diagnosed experience on a day-to-day basis.” (INT-10)

Some participants highlighted the relevance of the items to the current health-related challenges faced by adults living with HIV:

“[Other questionnaires] seem to be out-dated. They’re probing but it doesn’t seem to be really capturing the essence of what a person’s going through... This one does.” (INT-22).

Purpose of the HDQ

Participants felt that clinicians and community-based organizations could use the HDQ to better understand the complexity of disablement that people living with HIV might experience and indicate other health providers, services or supports to refer individuals.

“gives a picture of myself from an HIV standpoint... gave me the opportunity to express what was going on... present a broad picture but then a more ‘what’s been going on with me lately’ also.” (INT-20)

“[The HDQ] can isolate what areas need to be looked at and where they might require support... will help people who are working with PHAs [people living with HIV/AIDS] to see the complexity...” (INT-13)

Adults living with HIV may use the HDQ to raise self awareness about the multi-dimensional nature of disability:

“gives you some insight as to the possibility that other things could be going on in the system rather than just physical” (INT-9)

The majority of participants living with HIV felt that the HDQ could be used to facilitate a conversation with health providers about the health-related challenges they might experience:

“... I do worry about [living with HIV] but I never talk about it.” (INT-19)

Similarly, clinicians felt the HDQ could be used for goal-setting and opening up dialogue with patients leading to referrals to other services if needed.

Face Validity

Participants remarked how they liked being asked questions in the **symptoms and impairments**

domain:

“because you don’t necessarily even get asked that kind of thing ... The assumption is made that things are kind of status quo unless you bring them up” (INT-9).

Participants also appreciated the questions in the **difficulties with day-to-day activities** domain:

“I thought that was excellent that was all brought up...cause that’s a subject that a lot of people... don’t get into talking to about everyday” (INT-10).

Participants particularly highlighted the importance of the uncertainty and social inclusion domains.

One participant highlighted how the **uncertainty** domain was especially relevant to his experience living with the episodic and unpredictable nature of HIV:

“this section about uncertainty deals really with something I worry about specifically around my HIV... about my viral load and CD4 count numbers, getting a serious illness, when my next illness is going to come. That’s bang on because to me personally I’ve had just one episode after another... and every time I thought I was turning a corner...every step... I took forward I took three steps backwards. So, these questions ...are just bang on, 'cause I worry about these things all the time now.” (INT-20)

Participants also highlighted the importance of the **social inclusion** domain, including challenges fulfilling parental roles, engaging in work or school, and navigating personal relationships:

“the last section around the psycho-social stuff relating to community, ability to connect with work force ... is also very important ... in terms of getting a whole rounded sense of the individual, not just from the physical ailments...” (INT-9)

Content Validity

Participants provided suggestions for revising item wording, content and response options.

For example, reducing double-barreled items (e.g. revising “I have stomach or muscle cramps” (item 14) into two separate items), adding an item on housing in the challenges to social inclusion domain (e.g. “I have difficulty maintaining stable housing”), and adding ‘not applicable’ response options for certain items that may not apply to all participants (e.g. for participants not responsible caring for anyone (item 59), not interested in embarking upon new intimate relationships (item 67), or not interested in returning to work (item 44)).

Ease of Use

Participants found the HDQ easy to complete:

“very straight forward...you can’t get more direct in some of these...I think the questions are

very concise and to the point and don't leave a whole lot of room for misinterpretation. Instructions were clear." (INT-20)

Overall, participants did not report any discomfort completing the HDQ.

"nothing makes me feel uncomfortable... but it's definitely point[ed] out a few things that I need to work on, which is a good thing" (INT-2).

Response Options

Participants found the seven point ordinal response options adequate:

"I always find it difficult when I have not enough choices in there... there's a lot of gray in between... so I felt this gave me enough of a range." (INT-20)

Format

Symptoms and impairments and difficulties with day-to-day activities domain were generic whereas items in the uncertainty and social inclusion domains were primarily HIV-specific.

Participants acknowledged that the items were negatively phrased such as: 'I have difficulty with'; 'I have problems'; or 'I worry about'. Participants commented on the use of first person ("I") throughout all items in the questionnaire

"you can really put yourself into the question I find, which is good." (INT-20)

Episodic Component of the HDQ

Overall participants felt that the HDQ captured the daily episodic nature of disability

"that was my favourite part of the survey... because I have good days...up and down.. The way I feel about myself is like it's a heart monitor. When it's up and down and jagged and just all over the place..." (INT-2)

Title of the HDQ

Some participants were unclear about the term disability or interpreted 'disability' as a label related to income support:

"Disability is one of those words I'm not sure a lot of us get" (INT-11)

"First of all, I'm thinking ODSP [Ontario Disability Support Program] right away, and so it's like, I'm not disabled! So why should I answer this questionnaire?" (INT-11).

Others supported the title HIV Disability Questionnaire remarking:

"well that's what the study's about. It's exactly as it should be" (INT-20).

While one clinician participant acknowledged the negative connotations associated with term disability as a label or link to income support, he felt it was important to retain the term 'disability'

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because it clearly and accurately reflected the concept of interest as previously defined by adults living with HIV.

“I kind of like it from the viewpoint because that’s what we are collecting here. I think it’s one of those double-edge swords ... where almost by using the word we’re helping maybe to demystify...or de-stigmatize it....by actually using the word are we helping people to ... reclaim the terminology and use it accurately...” (CLIN-3)

For Peer Review

Sensibility Assessment of the HIV Disability Questionnaire

Implications for Rehabilitation

- As people with HIV infection live longer, individuals may face a range of health related challenges due to the disease, concurrent health conditions, and the potential adverse effects of treatment. Together, these health challenges may be termed *disability*.
- The HIV Disability Questionnaire (HDQ) is the first HIV-specific instrument developed to describe the presence, severity and episodic nature of disability experienced by adults living with HIV. The HDQ is comprised of four domains including symptoms and impairments, uncertainty about future health, difficulties carrying out day-to-day activities, and challenges to social inclusion.
- The HDQ appears sensible for use with adults living with HIV, possessing face and content validity and ease of use in all four domains as well as describing the daily episodic nature of disability.
- The HDQ may be used by rehabilitation clinicians and researchers to assess disability experienced by adults living with HIV.