


Examining the Utility of the HIV Disability Questionnaire (HDQ) in Clinical Practice: Perspectives of People Living with HIV and Healthcare Providers

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Kyle Vader, MScPT, PT^{1,2} , Soo Chan Carusone, PhD³,
Rachel Aubry, MSc⁴, Puja Ahluwalia, MPH, PT⁵,
Carolann Murray, BScPT, PT³, Larry Baxter, BA⁶,
Gregory Robinson, MD, MSc⁷, Francisco Ibáñez-Carrasco, PhD⁸,
Ann Stewart, MD, MSc^{9,10}, Patricia Solomon, PhD, PT¹¹ , and
Kelly K. O'Brien, PhD, PT^{4,12,13} 

Abstract

Our aim was to examine the utility of the HIV Disability Questionnaire (HDQ), a patient-reported outcome measure for use in clinical practice from the perspectives of people living with HIV (PLWH) and healthcare providers. We conducted a qualitative descriptive study. Fifteen PLWH and five healthcare providers participated in an interview, of which ten PLWH participated in a follow-up focus group discussion. The HDQ has value in clinical practice, including its role in assessing disability, facilitating communication, tailoring treatments, and guiding referrals. Strengths of the HDQ included its comprehensiveness, relevance of domains, and importance of specific items. Concerns related to length of the HDQ, the potential for some items to trigger emotional response, and negative connotations with the term 'disability.' Recommendations for HDQ implementation included the importance of score interpretability, shortening the questionnaire, and tailoring administration to the individual. Results suggest the HDQ possesses clinical utility with PLWH and healthcare providers.

Keywords

Surveys and questionnaires, human immunodeficiency syndrome, disability, rehabilitation, clinical utility

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¹ School of Rehabilitation Therapy, Queen's University, Kingston, ON, Canada

² Chronic Pain Clinic, Kingston Health Sciences Centre, Kingston, ON, Canada

³ Casey House, Toronto, ON, Canada

⁴ Department of Physical Therapy, Temerty Faculty of Medicine, University of Toronto, Toronto, ON, Canada

⁵ Realize, Toronto, ON, Canada

⁶ Community Member, Halifax, NS, Canada

⁷ Community Member, Toronto, ON, Canada

⁸ Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada

⁹ St. Michael's Academic Family Health Team, Toronto, ON, Canada

¹⁰ Department of Family and Community Medicine, University of Toronto, Toronto, ON, Canada

¹¹ School of Rehabilitation Science, McMaster University, Hamilton, ON, Canada

¹² Rehabilitation Science Institute, University of Toronto, Toronto, ON, Canada

¹³ Institute of Health Policy, Management, and Evaluation, Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada

Corresponding Author:

Kelly K. O'Brien, Department of Physical Therapy, University of Toronto, 150-500 University Avenue, Toronto, ON M5G 1V7, Canada.

Email: kelly.obrien@utoronto.ca



Introduction

People living with HIV (PLWH) who have access to effective combination anti-retroviral therapy (cART) are now living longer with a combination of health-related challenges due to HIV, aging, and multi-morbidity, commonly described as disability.^{1–5} Disability among PLWH has been conceptualized as the fluctuating physical, mental, and social day-to-day health-related challenges associated with living with HIV.^{6,7}

Disability, including impairments, activity limitations, and participation restrictions, is common among PLWH in both low-/middle- and high-income countries.^{8–10} A cross-sectional study examining the prevalence of disability among PLWH in British Columbia, Canada found that over 90% of PLWH experienced one or more impairments, such as weakness, chronic fatigue, and decreased endurance.¹¹ Furthermore, Myezwa and colleagues found that over 50% of PLWH in South Africa reported functional limitations in their day-to-day life.¹² Emerging evidence also suggests that specific factors, such as pain and depression, may have an important mediating role in the development of disability among PLWH.¹³

The Episodic Disability Framework is a conceptual framework developed from the perspectives of PLWH that describes dimensions of disability experienced by PLWH, including symptoms or impairments, difficulties with day-to-day activities, challenges to social inclusion, and uncertainty about future health, which can fluctuate from day-to-day as a result of intrinsic factors as well as extrinsic factors.^{6,7} The dimensions of disability described within the Episodic Disability Framework have been validated among PLWH and provide a scaffold to measure disability in this population.¹⁴

Given the prevalence and multi-dimensional nature of health-related challenges experienced by PLWH,¹¹ it is important to measure the nature and extent of disability.¹⁵ Measurement of disability can help to understand the health related challenges experienced by PLWH.¹⁵ Patient-reported outcome measures (PROMs) have an important role in HIV care as they can improve symptom recognition, measure effectiveness of treatment interventions, and facilitate communication between PLWH and healthcare providers.¹⁶ Furthermore, the use of PROMs in routine HIV care can improve the delivery of person-centered care.¹⁷

The HIV Disability Questionnaire (HDQ) is a 69-item HIV-specific PROM developed from the dimensions of the Episodic Disability Framework.¹⁸ The purpose of the HDQ is to describe the presence, severity, and episodic nature of disability experienced by PLWH.¹⁸ The HDQ contains six domains: (i) physical, (ii) cognitive, (iii) mental-emotional health symptoms and impairments, (iv) difficulties carrying out day-to-day activities, (v) uncertainty and worrying about the future, and (vi) challenges to social inclusion.^{19,20} The HDQ has been validated in multiple geographic contexts, including PLWH in the United States,²¹ Canada and Ireland,²² and the United Kingdom.²³

To date, the HDQ primarily has been used in the context of research. It is unclear how the HDQ may be used within clinical

practice for PLWH. The purpose of this research was to examine the utility of the HDQ in clinical practice from the perspectives of PLWH and healthcare providers.

Materials and Methods

Study Design

We conducted a qualitative descriptive study.^{24,25} This research was situated as part of a larger study exploring the implementation of physiotherapy and an HIV-specific PROM (the HDQ) within a community-based HIV care setting.²⁶ The research team included multiple stakeholder groups, including PLWH, healthcare providers, individuals from non-governmental organizations (NGOs), and researchers.

Ethical Approval and Informed Consent

We obtained ethical approval from the University of Toronto HIV/AIDS Research Ethics Board (REB Protocol Number: 36717). All individuals who participated in this research provided written informed consent prior to their participation.

Participants, Sampling, and Recruitment

Participants and Sampling: Participants included (1) PLWH who had accessed physiotherapy from a community-based HIV facility in Toronto, Canada and (2) healthcare providers from the community-based HIV facility and healthcare providers who commonly referred PLWH to programs at this facility. It was not an inclusion criterion that PLWH and healthcare providers participants had to have completed the HDQ as PLWH participants completed the HDQ prior to the interview and healthcare provider participants were given time to review the HDQ prior to the interview. We recruited participants using a purposive sampling technique.²⁷ We specifically recruited PLWH participants who had engaged in physiotherapy as part of their care from the community-based HIV facility because the physiotherapist administered the HDQ as part of routine care. The physiotherapist typically completed the HDQ in the first or second session with a patient as part of their assessment.

Recruitment of PLWH: Healthcare providers from the community-based HIV facility notified PLWH about the research study and obtained consent from interested individuals to share their name and contact information with the research coordinator. Upon agreement, the research coordinator contacted potential participants. PLWH who participated in an interview were subsequently invited by the research coordinator to participate in a focus group.

Recruitment of Healthcare Providers: A research coordinator contacted healthcare providers from the community-based HIV facility as well as healthcare providers who commonly referred PLWH to programs at this facility to request their participation in this study.

Data Collection

We used a combination of semi-structured interviews (with PLWH and healthcare provider participants)²⁸ and focus groups discussions (with returning PLWH participants).²⁹ The aim of the focus groups was to explore the utility of the HDQ in clinical practice in greater detail within a group-based setting. All interviews and focus groups were audio recorded, transcribed verbatim, and reviewed for accuracy (See Box 1 for questions from the semi-structured interview guide for PLWH participants, Box 2 for questions from the focus group discussion guide for PLWH participants, and Box 3 for questions from the semi-structured interview guide for healthcare provider participants).

Semi-structured Interviews: Interviews were conducted in-person by the first author (KV) at the community-based

Table 1. Characteristics of Participants Living with HIV (n = 15).

Characteristic	Description
Median age in years (25-75 th percentiles)	57 (55, 64)
Gender, n (%)	
Man	8 (53%)
Woman	6 (40%)
Fluid	1 (7%)
Ethnocultural group, n (%)	
Caucasian-White	8 (53%)
Latin American, Hispanic or Latino	2 (13%)
Other (eg, Italian, Persian, Portuguese)	5 (33%)
Living alone, n (%)	12 (80%)
Average gross yearly income (CAD), n (%)	
<\$10 000	2 (13%)
\$10 000-\$20 000	10 (67%)
\$20 000-\$30 000	2 (13%)
\$30 000-\$40 000	1 (7%)
Employment status, n (%)	
Employed	1 (7%)
Retired	5 (33%)
Unemployed	8 (53%)
Other	1 (7%)
Highest level of education achieved, n (%)	
High school diploma	3 (20%)
Trade or technical program	2 (13%)
College diploma	1 (7%)
Undergraduate degree	1 (7%)
Graduate degree	4 (27%)
Median year of HIV diagnosis (IQR)	1995 (1984, 2010)
Most recent viral load reported as undetectable, n (%)	13 (87%)
Median number of reported concurrent health conditions (IQR)	7 (3, 12)
Commonly reported concurrent health conditions (>30% of participants), n (%)	
Mental health condition	10 (67%)
Muscle pain	9 (60%)
Joint pain	9 (60%)
Hypercholesterolemia	7 (47%)
Asthma	5 (33%)
Hypertension	5 (33%)

HIV facility in a private room. The interviewer took field notes throughout the interviews.

Focus Group Discussions: Focus groups were conducted in-person by the first author (KV) and another member of the research team (RA) at the community-based HIV facility in a private room. The focus group facilitators (KV and RA) took field notes in both focus groups.

HDQ: Prior to the interviews, we administered a paper-based version of the HDQ to PLWH participants, and we asked healthcare provider participants to review the HDQ. At the beginning of the focus group, we asked PLWH participants to review a paper-based version of the HDQ and write down ideas to discuss.

Demographic Questionnaire: We administered a demographic questionnaire to gather information to describe characteristics of both participant groups, including PLWH and healthcare providers.

Data Analysis

Interview and Focus Group Data: We analyzed interview and focus group data using inductive content analysis as described by Elo and Kyngäs, including preparation, organizing, and reporting.³⁰ We used MAXQDA (VERBI Software; Version 12; 2015) to assist with data management and analysis. In the first step of analysis (preparation), the first author (KV) reviewed each interview and focus group transcript to familiarize themselves with the data. In the second step (organizing), a subset of the research team (KV, SCC, RA and KKO) created an initial coding scheme by independently coding two transcripts, including a PLWH and healthcare provider participant. This initial coding scheme was reviewed and refined by the same subset of the research team (KV, SCC, RA and KKO) prior to coding the remaining transcripts. The remaining interview and focus group transcripts were independently coded by the first author (KV) and at least one other member of the research team (SCC, RA, PA, LB, FIC, PS or KKO). We then held an in-person meeting with the research team (KV, SCC, RA, PA, LB, FIC, PS and KKO) to discuss each interview and focus group transcript. To facilitate deeper knowledge of each transcript, we created summaries of participant characteristics and HDQ scores that we reviewed when discussing each transcript. Following this meeting, the first author (KV) reviewed all coded transcripts and grouped codes from each interview and focus group transcript into broader categories and sub-categories through an iterative process. In the third and final step of analysis (reporting), we created a report with categories and sub-categories related to utility of the HDQ in clinical practice. We used multiple strategies to enhance the rigor of our findings. For example, we engaged in reflexive dialog as a research team throughout data collection and analysis, included diverse stakeholders in the analysis process (ie, PLWH, healthcare providers, individuals from NGOs, and researchers), and used supporting quotations to demonstrate our findings.³¹

HDQ: We calculated a presence, severity, and episodic score for the six domains of the HDQ for each PLWH participant to

describe health challenges (disability) experienced by the participants. Domain scores were calculated using a simple sum, transformed on scale of 0-100 with higher scores indicating a greater presence, severity and episodic nature of disability.^{20,21} We then calculated the median and 25-75th percentiles across each domain for all PLWH participants.

Demographic Questionnaire: We analyzed data from the demographic questionnaire using descriptive statistics (ie, frequencies and percentages for categorical variables and medians and 25-75th percentiles for continuous variables).

Results

We conducted interviews with fifteen (n = 15) PLWH and five (n = 5) healthcare providers between January to July 2019. Of the 15 PLWH who completed an interview, ten participated in one of two focus group discussions in March and May of 2019. Most PLWH participants were men (53%) with a median year of HIV diagnosis of 1995 (IQR: 1984, 2010) and were living with a median of seven comorbidities in addition to HIV (IQR: 3, 12). Healthcare provider participants represented nursing (n = 1), social work (n = 1), physiotherapy (n = 2), and family medicine (n = 1). The two physiotherapists had used the HDQ in clinical practice, while the remaining healthcare provider participants had not. Four healthcare providers participants worked within the community-based HIV facility, while one healthcare provider participant commonly referred PLWH to programs at

the facility. See Table 1 for more characteristics of the PLWH participants.

PLWH took approximately 10 to 25 min to complete the HDQ prior to their interviews. For the PLWH participants, the highest HDQ disability presence score was in the cognitive symptoms and impairments domain, whereas the highest disability severity score was in the difficulties with day-to-day activities domain. Physical symptoms and impairments had the highest episodic score. See Supplemental File 1 for HDQ scores of the PLWH participants.

We constructed three categories (and subsequent sub-categories) related to utility of the HDQ in clinical practice. See Table 2 for a summary of our results.

Value and Strengths of Using the HDQ in Clinical Practice

Participants described the value of using the HDQ as a tool for assessing disability among PLWH, facilitating communication between PLWH and healthcare providers, and tailoring treatments and guiding referrals to healthcare providers and/or services. Participants also reported specific strengths of the HDQ, including its comprehensiveness, relevance of questionnaire domains, and the importance of specific questionnaire items.

Assessing Disability in Clinical Practice. Participants described that the HDQ would be a useful tool for assessing disability within the context of HIV care. For example, PLWH described how the HDQ would give healthcare providers a greater understanding of the fluctuating and uncertain health-related challenges experienced by PLWH:

“[The HDQ] gives a very simple view of the whole person. So it helps the practitioner to know the patient better, what problems they have, what they don’t have [...] It’s one of the windows to the patient.” PLWH-13

Healthcare providers also reported that the HDQ could be valuable to monitor and track changes in health-related challenges experienced by PLWH over time and valued how the HDQ examines disability broadly, including at the level of impairments, activity limitations, and participation restrictions:

“I would [use the HDQ] for assessment and screening. I would reassess [clients] with [the HDQ] and see if anything has changed after they’ve ideally accessed our program [...] I still think [the HDQ] would be a useful way to capture [client] progress on many different levels, not just impairments but the activity level and the participation level right.” HCP-5

Facilitating Communication Between People Living with HIV and Healthcare Providers. Participants described how the HDQ could be a tool to facilitate communication between PLWH and healthcare providers. PLWH shared how the HDQ would help some PLWH to share personal and/or sensitive information, such as challenges related to mental health and isolation,

Table 2. Summary of Categories (and sub-Categories) Related to Utility of the HDQ in Clinical Practice.

Category	Sub-category
Value and Strengths of Using the HDQ in Clinical Practice	<ul style="list-style-type: none"> Assessing disability in clinical practice Facilitating communication between people living with HIV and healthcare providers Tailoring treatments and guiding referrals to healthcare providers and/or services Comprehensiveness of questionnaire Relevance of questionnaire domains Importance of specific questionnaire items
Concerns of Using the HDQ in Clinical Practice	<ul style="list-style-type: none"> Length of the questionnaire Potential for some items to trigger an emotional response Concerns related to negative connotations with the term ‘disability’
Recommendations for Implementing the HDQ in Clinical Practice	<ul style="list-style-type: none"> Importance of score interpretability Shortening the questionnaire Tailoring frequency and mode of administration to the individual

that they may not otherwise bring up to their healthcare providers. Ultimately, PLWH described how the HDQ could help to open up a dialog between PLWH and healthcare providers:

“I think [the HDQ] could be a very useful tool to open up a dialogue with the client [...] So if you can answer things like this that may give clues to the caregiver about where you’re heading.” PLWH-6

PLWH also reported that they are more likely to be honest about their health-related challenges in a questionnaire format versus in a conversation with a healthcare provider, which was seen as a particular value of the HDQ in clinical practice:

“Here [with the HDQ] you answer and you have to put the truth [...] If we talk [to a healthcare provider], maybe because I feel shame [...] I can lie. But in the [HDQ], I can’t lie.” PLWH FG-2

Tailoring Treatments and Guiding Referrals to Healthcare Providers and/or Services. Participants reported that using the HDQ in clinical practice would allow healthcare providers to tailor treatments and facilitate referrals to appropriate healthcare providers and/or services for PLWH. By identifying specific health-related challenges, participants described how the HDQ could help to ensure that PLWH access the services they need to promote overall health and well-being. For example, PLWH described how the HDQ would help to guide treatment planning in clinical practice:

“[The HDQ] does have a lot of value because you’re learning way more about the person before you actually get to know them, so you know what to treat better, you know what angles to come ... like then you know to be more compassionate for somebody, be more supportive, to be a little bit more hard-lined or structural or whatever else. Like my worker could have used that to help me fulfill my goals better and connect with organizations that do that type of work.” PLWH-14

Similarly, healthcare providers reported that the HDQ has value in identifying services that PLWH could benefit from, based on their self-reported health-related challenges:

“A lot of times [the HDQ] would flag like oh this person would be great to see for social work, this person would really benefit from therapeutic recreation.” HCP-4

Comprehensiveness of Questionnaire. Participants described how a strength of the HDQ is that it is comprehensive and assesses multiple aspects of disability that are commonly experienced by PLWH. For example, PLWH described how one strength of the HDQ is that it has the ability to assess a broad spectrum of physical and social health-related challenges:

“I like that [the HDQ] focused on all sorts of challenges [...] Instead of being narrow minded, it was more broad. It [covered] a broad range of topics.” PLWH-15

Healthcare providers also reported that a strength of the HDQ is its comprehensiveness, whereby it assesses diverse health-related challenges experienced by PLWH that healthcare providers may not typically ask about, such as mood, coping, and uncertainty:

“[As a healthcare provider] you don’t always ask about [...] your mood or your ability to cope or you know other pieces and how that’s been over time. That whole idea of uncertainty and worry is a really big one.” HCP-1

Relevance of Questionnaire Domains. Participants reported that the six domains of the HDQ (ie, physical, cognitive, mental-emotional health symptoms and impairments, difficulties carrying out day-to-day activities, uncertainty and worrying about the future, and challenges to social inclusion) are relevant and important to consider when providing care for PLWH. For instance, PLWH described how the domains resonated with their own experiences living with HIV:

“I think [the HDQ is] a perfect questionnaire. I think it has really good information and it explains the disability factor. It explains what disability means HIV wise and how it applies.” PLWH-15

Healthcare providers also shared that the HDQ’s focus on uncertainty is an important domain that other health questionnaires do not capture:

“[T]he thing that [the HDQ] gives me that other [questionnaires] don’t is the uncertainty or worry about the future.” HCP-1

Importance of Specific Questionnaire Items. Participants described the importance of specific items within the HDQ that were relevant when providing clinical care for PLWH. Items viewed as important were diverse; however, questions related to pain, body image, side effects of treatments, mental health, and isolation were frequently highlighted as important. For example, PLWH reported how items related to treatment side effects are important for healthcare providers to consider when providing care to PLWH:

“Another really big disability problem [...] is the side effects of your treatment because that messes up everything. It’s a whole different world. You’re going through this stuff and you get tired of one drug and all that but you go through a lot and you have to adapt to it. It affects everything you do in your life.” PLWH FG-1

Healthcare providers also reported that the way in which the HDQ asks about fluctuations in health-related challenges is valuable given the episodic nature of HIV symptoms:

“I appreciate that [the HDQ] asks about fluctuations given that it’s an episodic illness.” HCP-3

Concerns of Using the HDQ in Clinical Practice

Despite the perceived value and strengths of the HDQ, participants described potential issues when using the HDQ in clinical practice. Concerns related to the length of the HDQ, the potential for some items to trigger an emotional response, and use of the term ‘disability.’

Length of the Questionnaire. Although participants expressed that a strength of the HDQ is its comprehensiveness, they also emphasized how the length of the HDQ was a barrier to use in clinical practice, from the perspective of a person completing the questionnaire as well as a healthcare provider administering the questionnaire. For example, PLWH described how the HDQ is a very long questionnaire:

“I get too tense when I think about all these pages that I have to do [with the HDQ].” PLWH-1

Similarly, healthcare providers expressed concerns about the length of the HDQ:

“Well my first impression has always been it’s way too long. I understand why it is long but for a clinician [...] you know, the scales that I routinely use in the office have between [...] five and ten questions and can be completed by a patient sitting in the waiting room.” HCP-1

Potential for Some Items to Trigger an Emotional Response. Although participants reported that the HDQ included important items that PLWH might not otherwise bring up to their healthcare provider, some items in the HDQ were perceived as having the potential to trigger an emotional response. For example, PLWH reported that some questions related to mental health, isolation, housing, and sexual relationships were perceived as sensitive in nature:

“I could see some of these questions being maybe a little bit triggering for somebody who might be homeless or have mental health issues. They might be triggering for someone who [...] has a lot of personal shame with HIV.” PLWH FG-2

Healthcare providers agreed that some aspects of the HDQ may trigger an emotional response for some PLWH:

“[S]ome [questions] might be triggering... I don’t know, like the physical or social or mental health stuff might be triggering in terms of like making [some] reflect on all their problems. It would need to be done carefully so that there’s like support afterwards.” HCP-3

Concerns Related to Negative Connotations with the Term ‘Disability.’ Some participants expressed concerns about the term ‘disability,’ stressing that there are negative connotations with the term in the HIV community. For example, some PLWH reported that the term can marginalize people:

“Well I think [the term] disability, I think it really kind of... it marginalizes people. So HIV, people were dying of AIDS you know 30 years ago but people now are living with HIV. They’re maintaining it. So I think when we use language like disability [...] it really pushes us back.” PLWH-2

One participant questioned whether ‘disability’ should be in the title of the HDQ:

“Well number one, I wouldn’t call it the HIV disability questionnaire. I’d call it the HIV status questionnaire or the HIV explorational questionnaire or something because disability puts on someone’s mind that you’re looking at disabilities, things that we can’t do or that we can no longer do because we’re HIV+.” PLWH-14

Healthcare providers also acknowledged that there may be some PLWH who do not identify as having a disability, which would need to be considered when using the HDQ in clinical practice:

“I think some [PLWH] might very much identify as having a disability and others might take issue with it somehow perhaps like not wanting to think about themselves as disabled.” HCP-3

Recommendations for Implementing the HDQ in Clinical Practice

Participants provided recommendations to support the implementation of the HDQ in clinical practice for PLWH, including the importance of score interpretability, shortening the questionnaire, and tailoring the frequency and mode of administration to the individual.

Importance of Score Interpretability. Participants recommended that in order for the HDQ to be valuable in clinical practice, it should provide meaningful and useable information for healthcare providers. For example, healthcare providers reported that the HDQ score should be able to guide treatment decision making:

“I think it’s [important to think of] what the clinicians would do with [the HDQ score ...] So what would you do with those answers [from the HDQ]? How would you adapt the care plan? How would you then work with the clients?” HCP-2

Healthcare providers described also how they would like to understand the meaning of specific scores in terms of disability severity:

“[I]f I did a depression scale [...] I would [know whether a] person has a high likelihood of depression. If I get a score here [with the HDQ ...] what does that mean [for] the level of disability?” HCP-1

Shortening the Questionnaire. A recommendation from participants was to shorten the length of the HDQ. Participants

reported that decreasing the number of items in each domain of the HDQ would make implementation in clinical practice more feasible. For example, PLWH reported that the domains of the HDQ are valuable, but they recommended decreasing the number of items within each domain:

“I think maybe the sections [of the HDQ] should be shortened. I think the sections are good, like the headlines in sections are good. But I think maybe the questions in the sections you could maybe take out one or two.” PLWH FG-2

Healthcare providers also recommended that the HDQ should be shortened to decrease burden and improve the ease of use in clinical practice:

“I just think [the HDQ is] very long [...] So like having a like one- to two-page [HDQ would be valuable ...] I think that’s really important. I think that could be beneficial.” HCP-2

Tailoring Frequency and Mode of Administration to the Individual.

Participants reported that the frequency and mode of administering the HDQ in clinical practice would depend on the individual completing the questionnaire. As such, participants described how healthcare providers should tailor their use of the HDQ based on characteristics of the individual, the frequency of administration, the mode of administration, and the extent of required support and guidance. Healthcare providers noted that some PLWH may need assistance completing the HDQ, while others may be able to complete it independently:

“I think that certain clients would really like to use a tablet [to complete the HDQ] but other ones might not have much experience with using them, like with using technology in general because they don’t have much money or much ability to access. So maybe they would have difficulty with a tablet [...] There might be problems with literacy with some of our clients.” HCP-3

Discussion

The HDQ is 69-item HIV-specific PROM that describes the presence, severity, and episodic nature of disability experienced by PLWH across six domains (ie, [i] physical, [ii] cognitive, [iii] mental-emotional health symptoms and impairments, [iv] difficulties carrying out day-to-day activities, [v] uncertainty and worrying about the future, and [vi] challenges to social inclusion).^{18–20} We found that the HDQ has value and specific strengths in clinical practice; however, PLWH and healthcare providers also highlighted some concerns and recommendations to consider when using the HDQ in clinical practice. Given the barriers to implementing PROMs in routine clinical care,^{32,33} our results provide information that can be used to facilitate the successful implementation of the HDQ in clinical practice.

The PLWH who participated in this research reported having a median of seven concurrent health conditions in addition to HIV, with the most common being mental health conditions,

muscle pain, and joint pain. This aligns with previous research that indicates PLWH can experience a higher prevalence of multi-morbidity than the general population.⁵ Furthermore, the highest HDQ disability presence score among PLWH participants was in the cognitive symptoms and impairments domain, the highest disability severity score was in the difficulties with day-to-day activities domain, and the highest episodic score was in the physical symptoms and impairments domain. As such, our results may be transferable to other healthcare contexts that provide care for PLWH who experience complex multi-morbidity and diverse health-related challenges.

Participants reported that the HDQ has value and specific strengths in clinical practice for PLWH. Given evidence suggesting that few PLWH access formal rehabilitation services, despite the need,³⁴ the HDQ may serve as an important tool to identify health-related challenges among PLWH, and in turn, serve as a tool to facilitate referrals to appropriate rehabilitation care, such as physiotherapy or occupational therapy. Our results reveal that the HDQ can be a valuable tool to guide person-centred care for PLWH, given that it may help to open lines of communication between healthcare providers and PLWH, particularly as it relates to sharing sensitive and/or personal information that may not be routinely asked by HCPs. Our findings align with previous research by Bristowe and colleagues whereby PLWH and healthcare providers identified the value of PROMs in HIV care, including their role in encouraging referrals to healthcare services.¹⁷ Participants in our research described specific strengths of the HDQ in clinical practice, including the relevance of questionnaire domains and the importance of specific items, particularly related to uncertainty and worrying about the future. This confirms earlier work whereby the HDQ demonstrated face, content, and construct validity among PLWH in Canada, United Kingdom, Ireland, and the United States.^{21–23,35} Furthermore, our finding that uncertainty is an important HDQ domain is supported with results from a national web-based survey and qualitative inquiry which identified uncertainty as a principal dimension of disability experienced by PLWH.^{36,37} Although uncertainty and worrying about the future may also be experienced by people living with other chronic and episodic health conditions (eg, rheumatoid arthritis and systemic lupus erythematosus³⁸), uncertainty is a central aspect of disability experienced by PLWH.^{36,37}

Despite the perceived value and strengths of the HDQ, participants shared concerns and described recommendations for implementing the HDQ within clinical practice. For example, some participants described concerns related to negative connotations with the term ‘disability’. This is an important consideration as use of the term ‘disability’ is not well established in the everyday vernacular about HIV and it is often theorized as an individual problem, while others propose that disability is greatly determined by institutions and societal structures.³⁹ Authors have also previously described perceived tensions around the term ‘disability’ in the context of HIV, whereby some PLWH expressed concerns about being labeled as ‘disabled,’ while at the same time acknowledging the importance

of having their health-related challenges recognized and validated by healthcare providers.⁶ To mitigate some of these concerns related to the term ‘disability,’ it is important for healthcare providers who are administering the HDQ to clearly describe the purpose of the HDQ, whereby the goal is to measure health-related challenges experienced by PLWH, which can be fluctuating and episode in nature, and that the purpose of the HDQ is *not* to dichotomously label someone as ‘disabled’ or ‘not disabled.’ Future work should prioritize developing a clear guidance document on the purpose, use, and administration of the HDQ to ensure clear communication between the healthcare provider administering the HDQ and PLWH.

Participants described concern that some items on the HDQ may potentially trigger an emotional response. Healthcare providers administering the HDQ should ensure that they fully describe the types of questions included in the HDQ in the domains, adequately preface that some items may be sensitive in nature, and be prepared to support PLWH who experience an emotional response. Despite these concerns, participants in this study agreed that the HDQ has value to help facilitate the sharing of sensitive information between PLWH and healthcare providers that would otherwise be difficult to communicate, particularly on topics related to mental health and isolation. This aligns with previous work that described how PROMs can be useful in sharing sensitive information in the context of HIV care.¹⁷

A key recommendation to consider when implementing the HDQ in clinical practice was the importance of shortening the length of the HDQ. A shorter version of the HDQ may improve feasibility of use in clinical practice by decreasing the burden on PLWH who complete the questionnaire and healthcare providers who administer it.⁴⁰ Research is currently underway to develop a short-form version of the HDQ.⁴¹ Participants, particularly healthcare providers, also described the importance of score interpretability of the HDQ. Future research should prioritize developing a quick and user-friendly scoring system of the HDQ that can be easily interpreted by healthcare providers to guide treatment decisions.⁴² Future work should also determine the minimal clinically important difference in HDQ scores to allow healthcare providers and/or researchers to determine whether an intervention has been effective at addressing health-related challenges for PLWH in a clinically meaningful way.

Finally, participants in this research described the importance of tailoring the frequency and mode of administration of the HDQ to the individual. Implementing PROMs in routine clinical practice requires a number of considerations, including choosing a mode for administering the questionnaire.⁴³ In this research, we administered a paper-based version of the HDQ based on the population who accessed services at the community-based HIV facility, whereby many experienced complex multi-morbidity and challenges accessing technology. Remote and digital methods of questionnaire administration are particularly important given the rapid increase in remote methods of service delivery in the context

of COVID-19.^{44,45} Given potential accessibility challenges of electronically administering the HDQ (eg, challenges with access to technology and low technological literacy), electronic and web-based modes of the HDQ administration requires further exploration.

Limitations

Most participants were recruited from a community-based HIV facility in a large urban setting in Toronto, Canada. As such, the transferability of our results to other care settings (eg, acute care) and geographic contexts, such as low- and middle-income countries, is unclear. Future research should determine the clinical utility of the HDQ in other geographic contexts, including low- and middle-income countries, such as Sub-Saharan Africa. Furthermore, participants in this research had either engaged in physiotherapy within the community-based HIV facility (PLWH participants) or had worked collaboratively alongside rehabilitation providers in the context of HIV care (healthcare provider participants). Therefore, our results may not have captured the diversity of perspectives of PLWH and healthcare providers who are less familiar with concepts of disability and rehabilitation. Despite these limitations, this study provides important perspectives on the importance of PROMs as part of comprehensive, person-centred HIV care.

Conclusions

The HDQ possesses utility in clinical practice from the perspectives of PLWH and healthcare providers. Participants reported that the HDQ is a valuable tool for assessing disability in the context of HIV, facilitating communication between PLWH and healthcare providers, and tailoring treatments and guiding referrals to healthcare providers and/or services. Strengths of the HDQ included its comprehensiveness, relevance of questionnaire domains, and the importance of specific questionnaire items. Concerns of using the HDQ in its current form included the length of the questionnaire, potential for some items to trigger an emotional response, and concerns related to negative connotations with the term ‘disability.’ Recommendations for implementing the HDQ in clinical practice included the importance score interpretability, shortening the questionnaire, and tailoring the frequency and mode of administration to the individual. Results may be transferable to other healthcare contexts that provide care to PLWH who experience complex multi-morbidity and diverse health-related challenges. Next steps include developing a short-form version, considering interpretability of scores, and determining the ideal mode(s) of administration and score presentation to support implementation of the HDQ and communication of scores within clinical practice with PLWH.

Supplemental Questions

What do we already know about this topic? The HIV Disability Questionnaire (HDQ) is a 69-item HIV-specific patient-reported outcome measure (PROM) developed to describe the

presence, severity, and episodic nature of disability experienced by people living with HIV.

How does your research contribute to the field? To our knowledge, this is the first qualitative study to explore the clinical utility of the HIV Disability Questionnaire (HDQ) from the perspectives of people living with HIV and healthcare providers.

What are your research's implications toward theory, practice, or policy? Study results provide patient and healthcare provider perspectives towards the HIV Disability Questionnaire (HDQ) in clinical practice, including strengths, concerns, and recommendations for implementing the HDQ within clinical contexts.

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Declaration of Conflicts of Interest

The authors declared no potential conflicts of interest with respect to the research, authorship, or publication of this article.


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Data Availability

The data used and/or analyzed for this manuscript are available from the corresponding author on reasonable request.

ORCID iDs

Kyle Vader  <https://orcid.org/0000-0002-0667-9726>

Patricia Solomon  <https://orcid.org/0000-0002-5014-0795>

Kelly K. O'Brien  <https://orcid.org/0000-0002-1632-6537>

Supplemental Material

Supplemental material for this article is available online.

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Box 1. Questions from the interview guide for participants living with HIV.

1. Can you describe your experience completing the HDQ?
2. In what way was the HDQ used in your experience in the HIV community-based facility?
3. What do you think about how the HDQ asks about the fluctuations you might have experienced recently with your health challenges?
4. How might the HDQ be best used in clinical practice?

Box 2. Questions from the focus group discussion guide for participants living with HIV.

1. How well do the questions on the HDQ capture the types of disability you experience?
2. What do you think about the overall wording of the questions in the HDQ?
3. Each question has a few answer options you can choose from – did they capture the responses you wanted to give in order to describe your disability experience? Did you have any trouble with them?
4. How long did it take for you to complete the HDQ? What did you think of the length of time it took you to complete the questionnaire?
5. Were there any questions that you struggled to answer (and why)?
6. What do you think about the way in which the HDQ asks about fluctuations in health-related challenges?
7. We are interested in learning more about how the HDQ might be used in the clinical setting. How might the HDQ be best used in clinical practice?
8. What is the best way for healthcare providers to use the HDQ in their clinical practice?
9. What are the benefits of using the HDQ?
10. Do you see any challenges with using the HDQ?
11. The HDQ can be completed either on paper, or electronically in a tablet or computer format. What did you think about completing the HDQ on paper? What do you think about completing the HDQ on a tablet or computer?
12. Did you complete the HDQ alone or did some one assist you with it? In your opinion, who would be the best person to complete the HDQ with you? Why?
13. When do you think would be the ideal time to complete the HDQ? How often?

Box 3. Questions from healthcare provider participant interview guide.

Questions if participant had used the HDQ in clinical practice:

1. Can you describe your experience with the HDQ?
2. In what way was the HDQ used in your practice?
3. What do you think about the way in which the HDQ asks about fluctuations in health-related challenges?
4. To date the HDQ has primarily been used as a research tool. How might the HDQ be best used in clinical practice?
5. What are the benefits of using the HDQ?
6. Do you see any challenges with using the HDQ?
7. The HDQ can be completed either on paper, or electronically in a tablet or computer format. What did you think about patients completing the HDQ on paper? What do you think about them completing the HDQ on a tablet or computer?
8. When do you think would be the ideal time to complete the HDQ? How often?
9. Who do you think would be the ideal member of the team to administer the HDQ?

Questions if participant had not used the HDQ in clinical practice:

1. Can you describe your first impressions of the HDQ?
2. In what way might the HDQ be used in your practice? By who?
3. What do you think about the way in which the HDQ asks about fluctuations in health-related challenges?
4. To date the HDQ has primarily been used as a research tool. How might the HDQ be best used in clinical practice?
5. What are the potential benefits of using the HDQ?
6. Do you see any potential challenges with using the HDQ?
7. The HDQ can be completed either on paper, or electronically in a tablet or computer format. What did you think about patients completing the HDQ on paper? What do you think about them completing the HDQ on a tablet or computer?
8. When do you think would be the ideal time to complete the HDQ? How often?
9. Who do you think would be the ideal member of the team to administer the HDQ?