

Examining the Utility of the HIV Disability Questionnaire (HDQ) in Clinical Practice: Perspectives of Adults Aging with HIV and Health Care Providers

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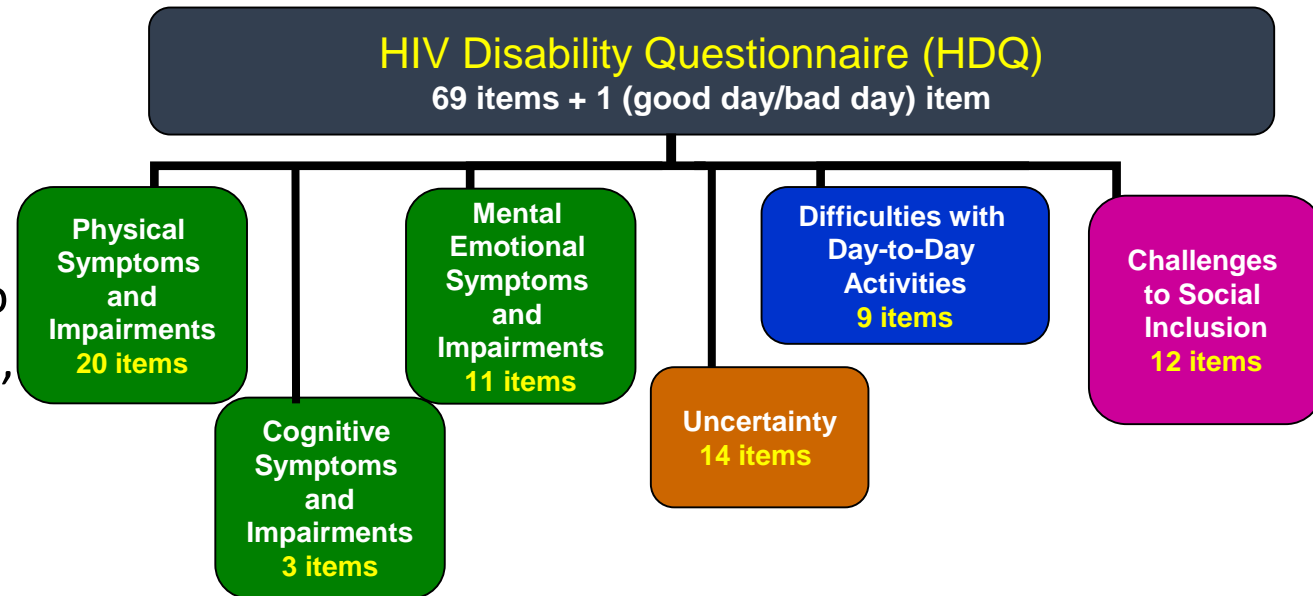


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Background & Purpose



- People living with HIV (PLWH) are living longer with the potential combination of physical, mental, and social health challenges associated with HIV, multimorbidity, and aging, known as disability.
- The HIV Disability Questionnaire (HDQ) is a 69-item patient-reported outcome measure developed to describe the presence, severity, and episodic multi-dimensional nature of disability.
- HDQ is newly emerging in clinical and community-based settings - it is important to evaluate the purpose, format, feasibility, and scope of this patient-reported outcome measure (PROM) in clinical practice.



Purpose: To examine the utility of the HDQ in clinical practice from the perspectives of people living with HIV and health care providers.

Methods



- We conducted a qualitative descriptive study at a specialty hospital in Toronto.
- **Semi-structured interviews:** i) adults living with HIV who received physiotherapy care and ii) health care providers working in HIV care.
- **Focus groups (HDQ Focus):** we invited participants living with HIV to return for one of two focus groups focused on the HDQ.
 - *Discussion questions:* experience completing the HDQ; perceived value in clinical practice, utility, timing and methods of administration (paper/tablet), interpretation of scores, recommendations for a short-form
- Demographic questionnaire + HDQ – administered with people living with HIV
- Data analyzed using conventional content analysis.

Interview & focus groups audio recorded, transcribed verbatim; reviewed for accuracy



Research team all reviewed one transcript and created initial coding scheme



Dyads of team members coded each transcript & focus group



1 Face-to-face + 2 teleconference meetings: discussed each transcript; identified themes

Adults living with HIV Characteristics	Interview (n=15)	Focus Group (n=10)
Median Age (IQR)	57 years (55, 64)	61 years (55,66)
Men	8 (53%)	6 (60%)
Women	6 (40%)	4 (40%)
Prefer no answer	1 (7%)	--
Median # of comorbidities (IQR)	7 (3,12)	7 (7,8)
Median Year of Diagnosis (IQR)	1995 (1984,2010)	1992 (1984, 2007)
Viral load undetectable	13 (87%) (n=1 missing)	9 (90%)

HDQ Domains with Highest Scores:

Presence Score (Cognition); Severity Score (Daily Activities); Episodic Score (Physical)

Health care provider Characteristics	Interviews (n=5)
Physiotherapist	2 (40%)
Physician, nurse, social worker and/or case manager	3 (60%)

HDQ STRENGTHS & UTILITY

- HDQ possesses value for assessing disability (and changes of disability) in clinical practice;
- HDQ comprehensiveness, domain relevance, and item importance; *“accurate picture”*
- **Key Items:** were dependent on the participant (isolation; body image, pain, uncertainty, mental health, episodic good day / bad day item): *“uncertainty and worry is a really big one”*;
- **Utility & Timing:** Administered at assessment and follow-up, the HDQ can facilitate communication between patients and providers, guide referrals to services, and identify areas to target treatment interventions.

CHALLENGES

- Included: length, occasional assistance required to complete, and concerns of ‘disability’ as a potential label when living with a chronic condition.

FEASIBILITY & RECOMMENDATIONS

- **Mode of Administration:** will depend on the individual -paper vs tablet; clinic visit vs home
- **Interpretability of Scores:** health care providers commented on the importance of score interpretability to guide treatment.
- Participants recommended shortening the questionnaire, however item importance varied.

Conclusions

- The HDQ possesses clinical utility from the perspective of adults living with HIV and health care providers.
- Results are limited to a sample of community dwelling adults living with HIV and complex multimorbidity associated with physiotherapy in a day health program and health care providers experienced with HIV care.
- Next steps include developing a short-form version to enhance feasibility for use in clinical practice.

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