Assessing the Sensibility, Utility, and Implementation of a Short-Form Version of the HIV Disability Questionnaire in Clinical Practice Settings in Canada, Ireland and the United States: A Mixed Methods Study

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**Background & Purpose**

- People living with HIV are living longer with the potential combination of physical, mental, and social health challenges associated with HIV, multimorbidity, and aging, known as disability.

- **Disability**: Broadly defined by people living with HIV as any health-related challenge experienced living with HIV.

- **Short-Form HIV Disability Questionnaire (HDQ)** is a 35-item patient-reported outcome measure (PROM) developed to describe the presence, severity, and episodic multidimensional nature of disability across six domains.

- Domain scores range (0-100): Higher scores indicate greater presence, severity and episodic nature of disability.

**Purpose**: To assess the sensibility, utility and implementation of the SF-HDQ in clinical practice.

**Short Form HIV Disability Questionnaire (SF-HDQ)**

- **35 items + 1 (good day/bad day) item**

  - **Physical Symptoms and Impairments**: 10 items
  - **Mental Emotional Symptoms and Impairments**: 5 items
  - **Difficulties with Day-to-Day Activities**: 5 items
  - **Challenges to Social Inclusion**: 7 items
  - **Uncertainty**: 5 items
  - **Cognitive Symptoms and Impairments**: 3 items

*How to access the questionnaire:*

Methods

Study Design: Mixed methods study with adults living with HIV (n=29) and HIV health care practitioners (n=16) in Canada, Ireland and United States.

3 Sites
• Casey House, Toronto, Ontario
• UHealth Infectious Disease Clinic, University of Colorado, Denver
• GUIDE Clinic, St. James’s Hospital, Dublin, Ireland

Data Collection: March 3, 2020 – February 17, 2021

E-Questionnaire Administration (Qualtrics)
• SF-HDQ
• Sensibility Questionnaire (19 items: face and content validity, ease of usage, format)

Semi-structured interviews (Zoom or In-Person): exploring potential sensibility, utility, and implementation considerations of SF-HDQ in clinical practice:
  ▪ Interview Guide: use of SF-HDQ in practice, experience completing or administering the SF-HDQ, strengths and challenges, feasibility, how and when to administer, who should administer, and how often (episodic nature of disability).

Analysis
Sensibility Questionnaire: SF-HDQ sensible if median scores were ≥5 for PLWH and ≥4 HIV health providers (7 point ordinal scale) for at least 80% of the items and if no items had median scores of ≤3 in either group.
Interview data: Group-based analytical approach using directed content analysis.

<table>
<thead>
<tr>
<th>Characteristics of Adults Living with HIV (n=29)</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (median years; IQR)</td>
<td>57 (51, 63)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Woman</td>
<td>10 (35%)</td>
</tr>
<tr>
<td>Man</td>
<td>19 (66%)</td>
</tr>
<tr>
<td>Country</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>10 (34%)</td>
</tr>
<tr>
<td>United States</td>
<td>10 (34%)</td>
</tr>
<tr>
<td>Ireland</td>
<td>9 (31%)</td>
</tr>
<tr>
<td>Live alone</td>
<td>14 (48%)</td>
</tr>
<tr>
<td>Have children</td>
<td>12 (41%)</td>
</tr>
<tr>
<td>Employed (full or part time)</td>
<td>7 (24%)</td>
</tr>
<tr>
<td>Retired</td>
<td>5 (17%)</td>
</tr>
<tr>
<td>Undetectable Viral load (&lt;50 copies/mL)</td>
<td>26 (90%)</td>
</tr>
<tr>
<td>Median # (IQR) concurrent health conditions</td>
<td>7 (4, 10)</td>
</tr>
<tr>
<td>Common conditions (&gt;30% of sample)</td>
<td></td>
</tr>
<tr>
<td>Mental Health Condition</td>
<td>17 (59%)</td>
</tr>
<tr>
<td>Trouble Sleeping</td>
<td>16 (55%)</td>
</tr>
<tr>
<td>Chronic Pain</td>
<td>15 (52%)</td>
</tr>
<tr>
<td>Self-Reported General Health</td>
<td></td>
</tr>
<tr>
<td>Excellent or Very Good</td>
<td>16 (55%)</td>
</tr>
<tr>
<td>Good</td>
<td>7 (24%)</td>
</tr>
<tr>
<td>Fair or Poor</td>
<td>5 (17%)</td>
</tr>
</tbody>
</table>

| HIV Health Care Practitioners (n=16)          | N (%) |
| Canada 5; Ireland 6; United States 5         |       |
| Physician                                    | 5 (31%) |
| Social Worker                                | 3 (19%) |
| Nurse                                        | 3 (19%) |
| Physiotherapist                              | 2 (12%) |
| PT Resident; Massage therapist; Pharmacist   | 3 (19%) |
Sensibility

- Sensibility Questionnaire
  - Median sensibility scores were ≥5/7 (adults living with HIV; n=29) and ≥4/7 (HIV clinicians; n=16) for 18/19 (95%) items.

- Interview Data
  - SF-HDQ represents the health-related challenges of living with HIV and other concurrent health conditions (where HIV was not the source of disability)
  - HIV specificity of items – difficulties attributing source of health challenges
  - Captured daily episodic nature
  - Easy to use / complete

"I think almost all of [the items] capture something important that a lot of our clients’ experience.” (HCP)

[The question about fluctuations] is probably one of the best questions. (PLWH)

Clinical Utility

Interview Data

- measuring health challenges and change over time
- guiding referral to specialists and services
- informing goal setting
- facilitating communication
- fostering multi-disciplinary approach to care.

- create a roadmap on how to treat [an] individual to get to an optimal outcome (PLWH)
- start a conversation towards something that maybe they didn’t realize was there. (PLWH)
- global assessment, to look at the overall wellness of the patient and identify things to work on through the next year (HCP)
- reminds us of the importance of the overall wellness and that taking the time to think outside the box (HCP)
- highlight things that maybe the patient hasn’t thought to bring up with the clinician (HCP)
Implementation Considerations & Conclusions

Administration Considerations
• Burden of administration - Time, conundrum of identifying health challenges with limited resources to address, logistical issues of internet, space
• Importance of person-centered approaches for tailoring the mode of administration
• Offering flexible options for modes of processes of administration - format, location, timing, and persons involved in administration

Communication of Scores
• Importance of considering personal preferences for communicating SF-HDQ scores among persons living with HIV and their health care practitioners
• Importance of explaining and interpreting SF-HDQ scores with persons living with HIV

Conclusions
- The SF-HDQ possessed sensibility and utility for use with adults living with HIV across the 3 clinical settings in Canada, Ireland and the United States.
- Assessment limited participation to individuals who had access to, and had comfort with, the use of technology to complete the questionnaires in a web-based format.
- Next steps: refinement of the SF-HDQ to the Episodic Disability Questionnaire (EDQ), future measurement property assessment (including interpretability) and development of a guidance document to facilitate implementation in clinical practice.

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