

HIV Disability Questionnaire (HDQ) Study Updates

The HIV Disability Questionnaire (HDQ) is the first HIV-specific questionnaire developed to describe the presence, severity and episodic nature of disability experienced by adults living with HIV.

The HDQ is also one of the few questionnaires to actively involve people living with HIV in its development. A Community Advisory Committee worked to ensure that the HDQ is culturally relevant, sensitive and applicable to people living with HIV.

The HDQ will help to identify health-related challenges experienced by people living with HIV and evaluate interventions aimed at reducing the severity and impact of their disability.

What do we mean by “disability”?

Disability refers to health-related challenges, such as

- physical symptoms (e.g. fatigue, weakness);
- cognitive symptoms (e.g. difficulty remembering);
- mental and emotional symptoms (e.g. feeling sad or depressed);
- difficulties carrying out day-to-day activities;
- feelings of uncertainty or worrying about the future; and
- difficulties participating in society (e.g. employment or engaging in relationships).

Sensibility, Reliability and Validity of the HDQ

Before any questionnaire is ready to be used, it needs to go through a study of its “measurement properties.”

The HIV Disability Questionnaire underwent such an assessment and was found to meet the following criteria with adults living with HIV in Southern Ontario:

- **Sensibility** – The HDQ is meaningful to people living with HIV and is easy to use.
- **Validity** – The HDQ measures what it is supposed to measure, namely disability.
- **Reliability** – The questions that refer to similar areas of the HDQ produce similar scores and the HDQ is consistent at measuring disability over time.

Dimensions and Areas of Disability covered by the HDQ. The HDQ covers three (3) dimensions of disability over six (6) areas, as described below.

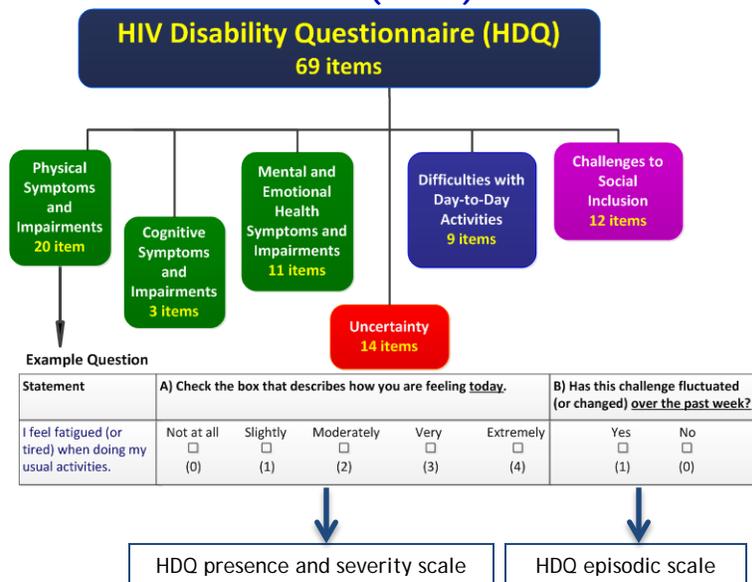
Dimensions of Disability

- **Disability presence** – the number of health-related challenges experienced.
- **Disability severity** – the degree to which health-related challenges are experienced.
- **Episodic nature of disability** – the number of health-related challenges that changed (got better, got worse, or both) within one week.

Areas (Domains) of Disability

- **Physical symptoms and impairments** – e.g. fatigue, weakness, diarrhoea, vision and hearing problems
- **Cognitive symptoms and impairments** – e.g. trouble concentrating, remembering or thinking clearly
- **Emotional and mental health symptoms and impairments** – e.g. feeling anxious, depressed, afraid, guilty, alone
- **Uncertainty and worry about the future** – from dealing with uncertainty surrounding test results and the side effects of medication, to worrying about body appearance, legal issues, and HIV transmission and criminalization
- **Difficulties with day-to-day activities** – from trouble with household chores, to difficulties with mobility and managing finances
- **Challenges to social inclusion** – from feeling cut-off from family, friends and networks, to struggling with safe and stable housing, starting new relationships and participating in the workforce

HDQ Domain Structure (Areas)



How Did Adults with HIV Score on the HDQ?

In a sample of over 360 adults living with HIV: **Highest disability presence and severity scores** tended to be in the uncertainty domain, followed by the cognitive and mental-emotional health challenges, challenges to social participation, physical health challenges, and difficulties with day-to-day activities domains.

Types of health challenges that tended to fluctuate most on a daily basis (highest episodic scores) were physical symptoms and impairments (fatigue, nausea and shortness of breath), followed by mental and emotional health symptoms and impairments (feeling sad, down or depressed, feeling anxious).

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How clinicians and AIDS Service Organizations (ASOs) may use the HDQ

The HDQ has the potential to become the first HIV-specific disability questionnaire used in HIV clinical research to assess the spectrum of disability experienced by adults living with HIV.

Once the HDQ is ready for use outside of a research setting, clinicians and ASOs could use the HDQ to better understand the complexity of health challenges experienced by their clients living with HIV. Being better able to assess the disability profile of people living with HIV – particularly with regard to areas of disability not addressed in existing questionnaires, such as living with uncertainty – may help clinicians and ASOs to identify gaps to be filled in programs, services and interventions.

What people living with HIV are saying so far about the HDQ

“Other questionnaires seem to be out-dated – they’re probing, but don’t seem to be really capturing the essence of what a person’s going through . . . the HDQ does.”

“The HDQ can isolate what areas of disability need to be looked at and where they might require support . . . it will help people who are working with PHAs to see the complexity . . .”

“The HDQ is very straightforward... you can’t be more direct in some of these questions . . . I think the questions are very concise and to the point and don’t leave a whole lot of room for misinterpretation.”

Next steps

The next phase in the development of the HDQ will be to determine these additional measurement properties:

- **Responsiveness** – Does the HDQ measure change in disability over time when a change occurs?
- **Interpretability** – What do the HDQ scores mean and what is their clinical importance?

In order to assess these properties, we are planning to develop a community-based exercise program for people living with HIV. We will use the HDQ to determine whether the questionnaire picks-up improvements in

disability (if improvements occur) and ask individuals to what extent the changes in their HDQ scores relate to the changes in their disability.

Recommendations

ASOs and clinicians should consider all dimensions of health-related challenges (or disability) a person might experience and consider the impact of the episodic nature in which these challenges might be experienced.

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 - Ontario Ministry of Health and Long-Term Care
- Robert Alexander
 - AIDS Committee of Ottawa
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 - Toronto People With AIDS Foundation

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