

Assessing the measurement properties of the HIV Disability Questionnaire (HDQ): Preliminary Perspectives from Canada and Ireland

International Forum on HIV and Rehabilitation Research

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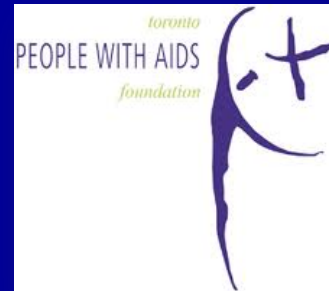
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Collaborator Organizations



Toronto PWA Foundation



Casey House



Canadian Working Group on HIV and Rehabilitation

Ontario Ministry of Health and Long-Term Care

AIDS Committee of Toronto



McMaster SIS Clinic and Family Practice Unit

Hamilton AIDS Network



Open Heart House, Dublin



Research Purpose

To develop and assess the measurement properties of a new HIV-specific questionnaire (HIV Disability Questionnaire) to describe disability experienced by adults living with HIV in Canada and Ireland

Phase 1 - HDQ Development

Dimensions of Episodic Disability



HIV Disability Questionnaire

- **Purpose:** To describe the presence, severity and episodic nature of disability experienced by adults living with HIV.
- **Characteristics**
 - 69 items – 4 domains
 - 1 item ('good day' or 'bad day' living with HIV)
- **Administration**
 - Self-reported questionnaire
 - Asks how individual is feeling *today*
 - Episodic nature: has challenge fluctuated (improved or worsened) *over the past week*

Sensibility Assessment

Face validity, content validity, ease of usage

Sensibility assessed

- 22 adults with HIV
- 5 clinicians who work in HIV care in Southern Ontario

Results provided considerations for HDQ revision:
item wording, content, terminology, and format.

HDQ Revision with Advisory Committee

Reviewed by Clear Language and Design (CLAD)

O'Brien KK, Bayoumi AM, Bereket T, Swinton M, Alexander R, King K, Solomon P. Sensibility Assessment of the HIV Disability Questionnaire. Disability and Rehabilitation. Eprint: July 2012.

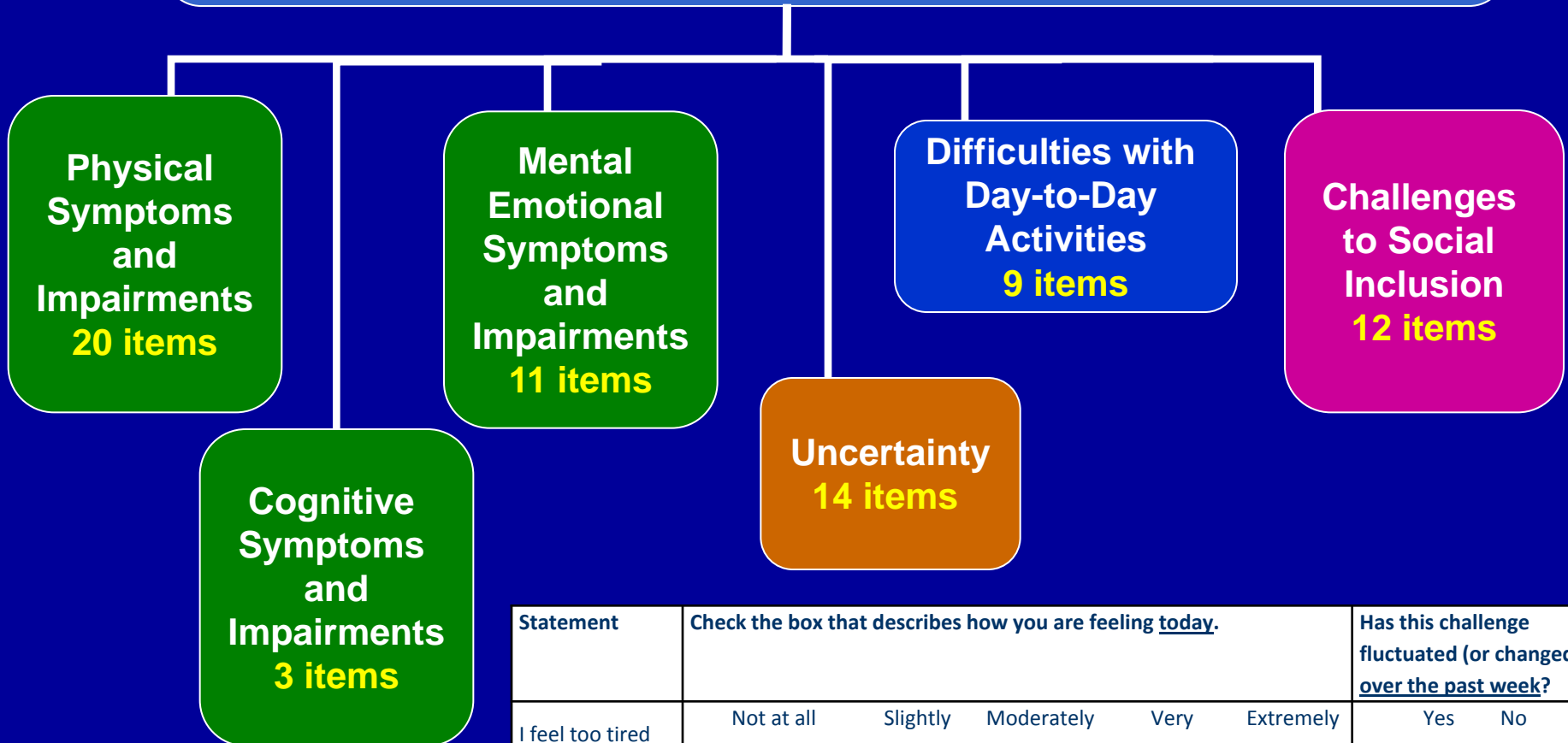
Phase 2 - What is the Domain Structure of the HDQ?

Factor Analysis - Statistical technique used to examine the underlying structure of a construct by identifying interrelationships among a set of item responses, and grouping them into dimensions that have common characteristics (Nunnally & Bernstein, 1994)

Recruitment: We recruited adults living with HIV from clinics and ASOs in Southern Ontario and administered the HDQ and demographic questionnaire (n=361 participants).

HDQ New Domain Structure

HIV Disability Questionnaire (HDQ) 69 items + 1 (good day/bad day) item



Statement	Check the box that describes how you are feeling <u>today</u> .					Has this challenge fluctuated (or changed) <u>over the past week?</u>	
	Not at all	Slightly	Moderately	Very	Extremely	Yes	No
I feel too tired to do my usual activities.	<input type="checkbox"/> (0)	<input type="checkbox"/> (1)	<input type="checkbox"/> (2)	<input type="checkbox"/> (3)	<input type="checkbox"/> (4)	<input type="checkbox"/> (1)	<input type="checkbox"/> (0)

Phase 3 - Measurement Properties

- 1) How well do questions in each domain 'hang together'? (internal consistency reliability)
- 2) How well is the HDQ at measuring what it's supposed to measure? (construct validity)
- 3) How consistent is the HDQ at measuring disability over time? (test-retest reliability)
[Toronto only]

Recruitment & HDQ Descriptives

HDQ Toronto (n=139)
(May-June 2011)

Site	Frequency (%)
Toronto	122 (88%)
Surrounding Areas	17 (12%)

HDQ Dublin (n=96)
(June-July 2012)

Site	Frequency (%)
GUIDE Clinic	89 (93%)
Open Heart House	7 (7%)

Administered the HDQ, seven health status and demographic questionnaires

- Median time to complete the HDQ (IQR)

Toronto	Dublin
10 min (8,12 minutes)	13 min (10,15 minutes)

Characteristics of Participants - 1

Characteristics	Toronto (#%) (n=139)	Dublin (#, %) (n=96)
Gender		
Men	114 (82%)	72 (74%)
Women	24 (17%)	23 (24%)
Other	1 (1%)	2 (2%)
Median age (years; IQR) # who were ≥ 50 years*	48 years (44,55) Range: 27-72 58 (41%)	41 years (34,48) Range:21-71 22 (23%)
Median year of diagnosis (IQR) Range*	1999 (1990, 2004) Range: 1981-2012	2003 (1998, 2009) Range: 1980-2012
# diagnosed prior to 1996*	58 (42%)	13 (14%)
# currently taking ARVs	127 (91%)	84 (88%)
# currently working for pay*	29 (21%)	52 (54%)

Characteristics of Participants - 2

Characteristics	Toronto (#, %) (n=139)	Dublin (#;%) (n=96)
Self rated health status		
Poor	12 (9%)	3 (3%)
Fair	35 (25%)	10 (10%)
Good	56 (40%)	21 (22%)
Very Good	25 (18%)	34 (35%)
Excellent	11 (8%)	26 (27%)
Median # of concurrent conditions*	4 (2,6)	1 (0,3)
Common Concurrent conditions (Top 5)	Muscle Pain - 77 (56%) Mental Health - 65 (47%) Joint Pain - 60 (44%) Addiction - 43 (31%) Neurocognitive Decline- 43 (31%)	Joint Pain – 22 (23%) Hepatitis C – 21 (22%) Muscle Pain – 21 (22%) Mental Health – 18 (19%) High BP – 16 (17%)
# with children	36 (26%) of which 11 (8%) live with them	33 (34%) of which 24 (73%) live with them
# who live alone*	91 (66%)	28 (29%)

Phase 3: Analysis

HDQ Scoring

- Disability presence score- summing # of health challenges experienced and transform out of 100 (range: 0-100)
- Disability severity score- summing individual item scores and then linearly transforming them out of 100
- Episodic score - summing # of challenges participants indicated fluctuated in the past week and transform out of 100
Higher scores indicated a greater presence, severity and episodic nature of disability.

Cronbach's alpha - internal consistency reliability of the HDQ.

Construct validity – correlation of HDQ and criterion scores

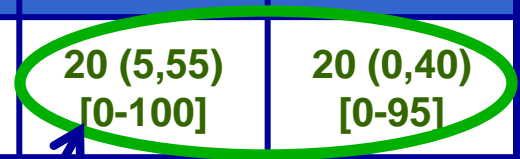
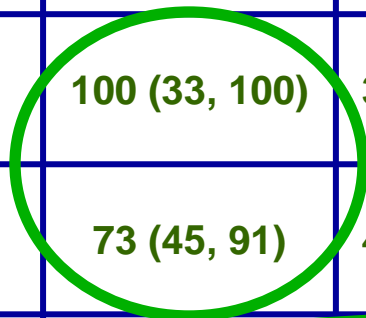
Test-retest reliability – Intraclass Correlation Coefficient (ICC)

Standardized Error of Measurement – HDQ items

HDQ Scores

Disability Dimension	Median Presence (Range 0-100) (IQR)		Median Severity Score (Range 0 to 100) (IQR)		Median Episodic Score (IQR, range)	
	Toronto	Dublin	Toronto	Dublin	Toronto	Dublin
Physical	60 (40-60)	35 (15,60)	25 (11, 38)	13 (5,25)	20 (5,55) [0-100]	20 (0,40) [0-95]
Cognitive	100 (33, 100)	33 (0,100)	25 (17, 42)	8 (0,25)	0 (0,67) [0-100]	0 (0,33) [0-100]
Mental-Emotional	73 (45, 91)	45 (18,80)	30 (13, 50)	14 (7,30)	9 (0,45) [0-100]	9 (0,36) [0-100]
Uncertainty	79 (57, 93)	71 (50,93)	39 (23, 61)	30 (18,53)	0 (0,29) [0-100]	0 (0,36) [0-100]
Difficulties with Day-to-Day Activities	56 (22, 89)	11 (0,22)	17 (6, 31)	3 (0,8)	0 (0,22) [0-100]	0 (0,0) [0-89]
Challenges to Social Inclusion	71 (50, 92)	42 (19,58)	31 (17, 50)	17 (7,29)	0 (0,17) [0-100]	0 (0,8) [0-92]
Total	68 (43, 81)	43 (26,59)	28 (16, 42)	17 (8,26)	12 (1,39) [0-100]	12 (3,28) [0-84]

Similar scores



What types of disability were episodic?

Highest episodic scores were reported in the symptoms and impairments domain – fluctuated in the past week

physical and mental-emotional health challenges.

Toronto		Dublin	
HDQ Items*	%	HDQ Items*	%
Fatigue	52%	Fatigue	38%
Feeling sad, down or depressed	44%	Aches and pains	37%
Nausea	39%	Feeling sad, down or depressed	35%
Aches and pains	37%		
Shortness of breath	36%		
Feeling anxious	35%		

*Items with at least 35% of the sample experiencing the challenge as episodic

Other Health Status Measures

Measure (Median, IQR)	Toronto (n=139) Median (IQR)	Dublin (n=96) Median (IQR)
World Health Organization Disability Assessment Schedule (WHODAS-II)* (Range 0-100)	30 (18,44)	12 (5,24)
SF-36 (Range 0-100)		
Mental Component Summary Score*	39 (32,49)	47 (38,54)
Physical Component Summary Score*	43 (35,50)	53 (43,57)
CES-D Summary Score* Range (Range 0-60)	23 (15,33)	13 (6,21)
HIV Symptom Index (Range 0-20)		
Total # present*	16 (11,19)	11 (5,15)
Total # bothersome*	13 (8,16)	7 (3,11)
HIV Stigma Scale (40-160)	103 (84,117)	99 (86,118)
MOS-Social Support Scale* Range (1-100)	49 (29,74)	63 (43,89)
Brief COPE		
Adaptive (Range 16-64)*	42 (36,48)	37 (30,45)
Maladaptive (Range 12-48)*	22 (19,28)	20 (16,24)

* statistical significant median difference indicated by p value <0.05.

Do the severity items 'hang' together?

(internal consistency reliability)

Score	Toronto Cronbach's Alpha (95% CI)	Dublin Cronbach's Alpha (95% CI)
Physical	0.918 (0.898, 0.937)	0.889 (0.857,0.922)
Cognitive	0.866 (0.819, 0.913)	0.837 (0.771,0.904)
Mental-Emotional	0.930 (0.911, 0.949)	0.909 (0.877,0.941)
Uncertainty	0.926 (0.906, 0.945)	0.921 (0.899,0.943)
Difficulty with Day-to-Day Activities	0.909 (0.833, 0.934)	0.885 (0.833,0.936)
Challenges to Social Inclusion	0.903 (0.877, 0.929)	0.897 (0.851,0.942)
HDQ Total (all items)	0.973 (0.967, 0.980)	0.965 (0.954,0.976)

Interpretation: $\alpha \geq 0.80$ defined as acceptable

HDQ demonstrates internal consistency reliability of the severity scale

Do the episodic items 'hang' together?

(internal consistency reliability)

Episodic Items	Toronto Kuder-Richardson (95% CI)	Dublin Kuder-Richardson (95% CI)
Physical	0.925 (0.908 , 0.942)	0.879 (0.838,0.921)
Cognitive	0.808 (0.735, 0.881)	0.841 (0.758,0.925)
Mental-Emotional	0.911 (0.887, 0.935)	0.901 (0.865,0.937)
Uncertainty	0.954 (0.939, 0.969)	0.945 (0.923,0.966)
Difficulty with Day-to-Day Activities	0.922 (0.891, 0.952)	0.847 (0.766,0.928)
Challenges to Social Inclusion	0.944 (0.922, 0.966)	0.897 (0.854,0.940)
HDQ Episodic Items (all)	0.978 (0.971, 0.984)	0.963 (0.950,0.976)

Interpretation: $\alpha \geq 0.80$ defined as acceptable

HDQ demonstrates internal consistency reliability of the episodic scale

Does the HDQ measure what it's supposed to measure?

Reference Measure	Toronto # hypotheses confirmed (%)	Dublin # hypothesis confirmed (%)
Convergent Construct Validity		
World Health Organization Disability Assessment Schedule	13/15 (87%)	9/15 (60%)
SF-36 Health Status Questionnaire	14/18 (78%)	13/18 (72%)
Divergent Construct Validity		
Social Support Scale	5/7 (71%)	0/7 (0%)
Total Confirmed	32/40 (80%)	22/40 (55%)
Known Groups Validity		
Participants who are older with more comorbidity will have higher HDQ scores.	2/2 (100%)	

HDQ demonstrates construct validity (measures what it's supposed to measure...disability)

Does the HDQ consistently measure disability? (Toronto only)

HDQ Domain	Intraclass Correlation Coefficient (ICC) (95% CI) Participants with no major change in health AND no change in good day/bad day item (n=99)
Physical	0.83 (0.64, 0.91)
Cognitive	0.80 (0.71, 0.86)
Mental-Emotional	0.88 (0.80, 0.93)
Uncertainty	0.85 (0.78, 0.90)
Difficulty with Day-to-Day Activities	0.86 (0.80, 0.90)
Challenges to Social Inclusion	0.89 (0.83, 0.92)
HDQ Total	0.90 (0.83, 0.94)

Interpretation: ICC of ≥ 0.70 defined as acceptable

HDQ consistently measures disability over time....

Conclusions – Descriptive HDQ Scores

- **Uncertainty** – Highest severity scores among Canadian and Irish participants.
 - appeared to be a key dimension of disability - not captured in other disability measures.
- **Physical symptoms and impairments** - dimension that fluctuated most on a daily basis.
- **HDQ severity and presence scores** – higher (more disability) among Canadian compared with Irish participants for all domains except uncertainty.

Conclusions – Measurement Properties

HDQ items 'hang together' in each domain

- **Internal Consistency Reliability**
 - Cronbach`s Alpha and KR-20 > 0.80 for all domains and total score

HDQ measures what it's supposed to measure....

- **Construct validity**
 - Construct validity testing (80% hypotheses confirmed in Toronto; 55% in Dublin; 100% known groups)

HDQ is consistent at measuring disability over time.

- **Test-retest reliability**
 - ICC > 0.70 for all domains and total score

Limitations and Considerations for Interpretation

- **Sample**
 - Primarily “healthy” adults with HIV
 - Ceiling effect on items
- **Recruitment** – ASOs in Toronto; Hospital clinic in Ireland
- **Differences in construct validity between samples**
 - may be due to lower HDQ scores among Irish participants (younger, less comorbidity), cultural differences, and differences in HDQ interpretation.
- HDQ does not distinguish between the source of health challenges (HIV-related versus concurrent health condition)

What we still don't know...Next Steps

- What do the HDQ scores really mean? - Interpretability
- Does the HDQ measure CHANGE in disability when change occurs? - Responsiveness
 - Pilot Intervention Study - Developing a pilot community based exercise intervention



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