

Reliability and Validity of the HIV Disability Questionnaire (HDQ) with Adults Living with HIV in Canada and Ireland

Kelly O'Brien, Patty Solomon, Colm Bergin, Siobhan O'Dea, Paul Stratford, Nkem Iku, Ahmed Bayoumi



ST. JAMES'S
HOSPITAL



UNIVERSITY OF
TORONTO

University of Toronto; McMaster University; St. James's Hospital (Dublin, Ireland), St. Michael's Hospital

Session: HIV and Aging

November 19, 2013 – 10:00am



St. Michael's
Inspired Care.
Inspiring Science.



OHTN 2013
RESEARCH
CONFERENCE

NOVEMBER 17-19, 2013

CHANGING THE COURSE OF THE
HIV PREVENTION, ENGAGEMENT AND
TREATMENT CASCADE

Acknowledgements



Funding: Canadian Institutes of Health Research
Michael DeGroote Postdoctoral Fellowship (McMaster)
Dobbin Scholarship (Ireland Canada University Foundation)

Knowledge Users / Community Advisory Committee

Ken King (CWGHR)
James Murray (MOHLTC)
Shane Patey (Toronto PWA)
Rob Alexander



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)



Canadian Working Group on HIV and Rehabilitation
Groupe de travail canadien sur le VIH et la réinsertion sociale

Research Purpose

To assess how well the
HIV Disability Questionnaire (HDQ)
measures disability experienced by adults
living with HIV

Specific Research Objectives

To assess the measurement properties of the HDQ

1) Internal Consistency Reliability

How well do questions in each domain 'hang together'?

2) Construct Validity

How well is the HDQ at measuring what it's supposed to measure?

What do we mean by Disability?

Definition

Any health-related challenge some might experience living with HIV or other condition including:

- Symptoms and Impairments
 - Uncertainty or Worrying about the Future
 - Difficulties with Day-to-Day Activities
 - Challenges taking part in social and community life (social inclusion)
-
- Challenge can be related to HIV or other related conditions, comorbidities, or aging
 - Challenges may be experienced as episodic in nature or fluctuate over time.

HIV Disability Questionnaire

Purpose: To describe the presence, severity and episodic nature of disability experienced by adults living with HIV.

Characteristics

- 69 items – 6 domains
- 1 item ('good day' or 'bad day' living with HIV)

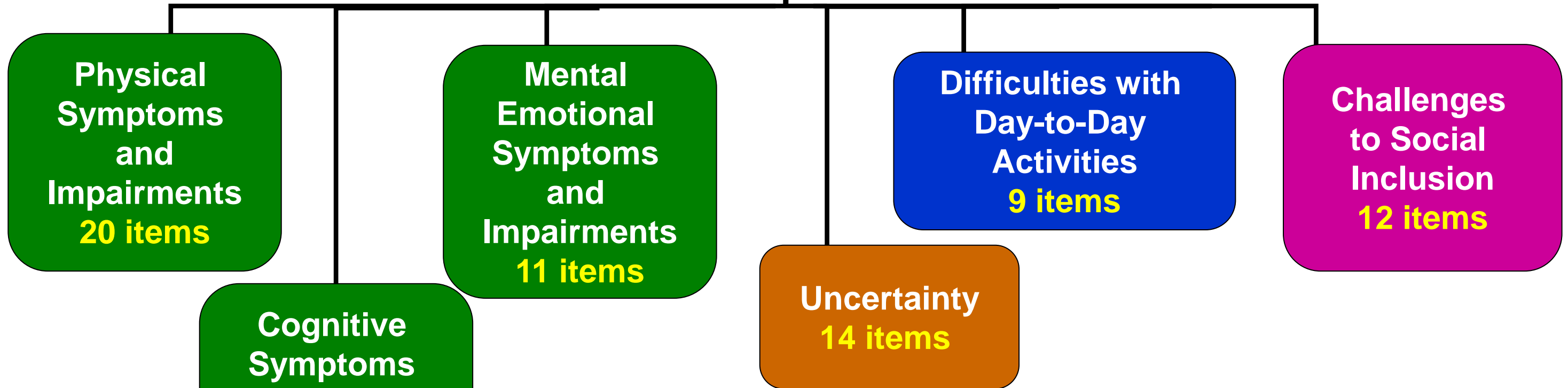
HDQ Development

- Item generation – Episodic Disability Framework
- Community Advisory Committee
- Sensibility Assessment
 - PHAs (n=22) and Clinicians who work in HIV Care (n=5)
 - Face validity, content validity, ease of use

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.

HQ 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 fatigued or 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)

Recruitment

Adults Living with HIV (18 years of age or older)

Southern Ontario

- AIDS Service Organizations, Hospital Clinics, Specialty Hospital

Dublin Ireland

- Hospital Clinic – St. James’s Hospital
- Open Heart House

Questionnaire Administration

- HDQ
- WHO-Disability Assessment Schedule II
- SF-36
- MOS-Social Support Survey
- Demographic Questionnaire

Participants by Site

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

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

Majority recruited from AIDS Service Organizations

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

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

Median time to complete the HDQ (Interquartile Range)

Toronto	Dublin
10 min (8,12 minutes)	13 min (10,15 minutes) <i>measurement error likely</i>

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%)

*Bold indicates significant difference between participants

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)	<p>Muscle Pain - 77 (56%)</p> <p>Mental Health - 65 (47%)</p> <p>Joint Pain - 60 (44%)</p> <p>Addiction - 43 (31%)</p> <p>Neurocognitive Decline- 43 (31%)</p>	<p>Joint Pain – 22 (23%)</p> <p>Hepatitis C – 21 (22%)</p> <p>Muscle Pain – 21 (22%)</p> <p>Mental Health – 18 (19%)</p> <p>High Blood Pressure – 16 (17%)</p>
# 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%)

*Bold indicates significant difference between participants

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) Higher disability	12 (5,24)
SF-36 (Range 0-100)	Lower mental and physical QOL scores	
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)	Higher CES-D and Symptom Index scores	
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	Lower Social Support	
Adaptive (Range 16-64)*	42 (36,48)	37 (30,45)
Maladaptive (Range 12-48)*	22 (19,28)	20 (16,24)

Similar scores

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

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.

Measurement Properties

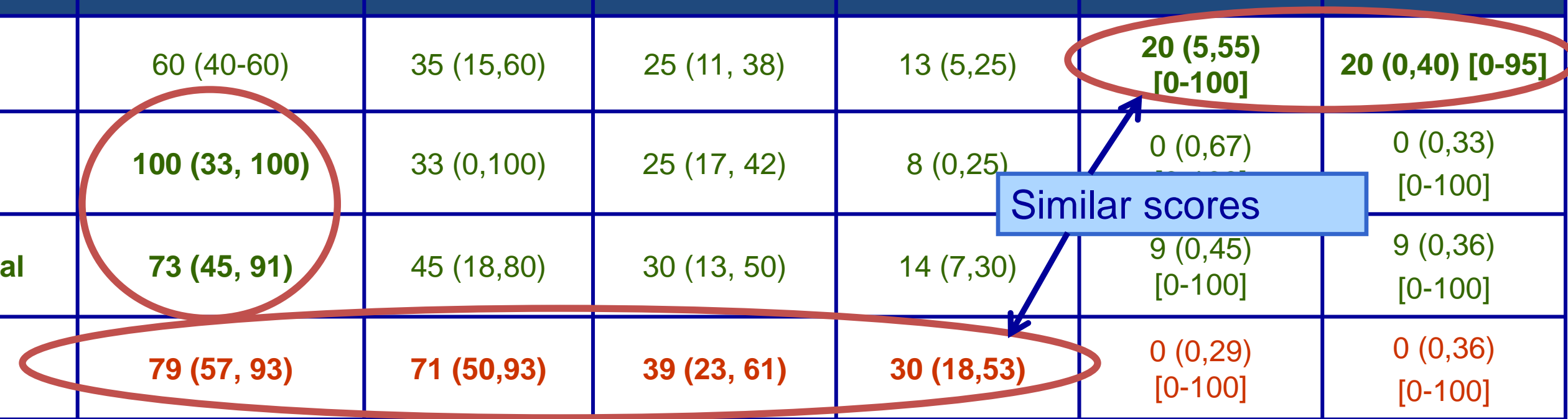
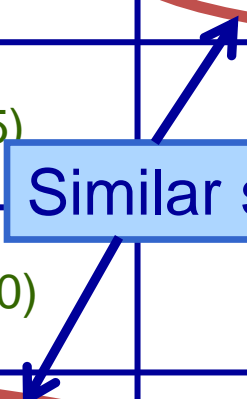
Cronbach's alpha and Kuder Richardson-20 - internal consistency reliability of the HDQ (>0.80 acceptable)

Construct validity - 40 a priori hypotheses of correlations between HDQ and health status questionnaire scores and 2 known group hypotheses based on age and comorbidity

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 (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

Internal Consistency Reliability

Do the severity items 'hang' together?

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) Low
Mental-Emotional	0.930 (0.911, 0.949) High	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

Internal Consistency Reliability

Do the episodic items 'hang' together?

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	Low	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	High	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

Construct Validity

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%)	

Interpretation: 75% confirmed defined as acceptable

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

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)

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,
 - differences in HDQ interpretation.

HDQ does not distinguish between the source of health challenges (HIV-related versus concurrent health condition)

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 with adults living with HIV
 - YMCA
 - Toronto PWA Foundation

Acknowledgements

- Canadian Working Group on HIV and Rehabilitation
- Casey House
- Ontario Ministry of Health and Long-Term Care
- Toronto PWA
- AIDS Committee of Toronto
- The AIDS Network (Hamilton)
- McMaster SIS Clinic
- St. Michael's Hospital
- AIDS Committee of Durham
- AIDS Committee of Niagara
- Fife House
- Black CAP
- GUIDE Clinic, St. James's Hospital
- Open Heart House

Funding

Canadian Institutes of Health Research

Michael G. DeGroote Postdoctoral Fellowship
McMaster University

Ireland Canada University Foundation



kelly.obrien@utoronto.ca