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Measuring Disability Experienced by Adults Living with HIV: Assessing Construct Validity of the HIV Disability Questionnaire using Confirmatory Factor Analysis

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1   **Measuring Disability Experienced by Adults Living with HIV: Assessing Construct**

2   **Validity of the HIV Disability Questionnaire using Confirmatory Factor Analysis**

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32 **Measuring Disability Experienced by Adults Living with HIV: Assessing Construct**

33 **Validity of the HIV Disability Questionnaire using Confirmatory Factor Analysis**

34 **ABSTRACT**

35 **Objectives**: To assess the construct validity of the HIV Disability Questionnaire (HDQ), a self-

36 administered questionnaire that describes the presence, severity and episodic nature of disability

37 experienced by people living with HIV.

38 **Design**: We conducted a confirmatory factor analysis. We hypothesized that domains in the

39 HDQ characterized six dimensions of disability, each represented by HDQ items: physical

40 symptoms and impairments (20 items); cognitive symptoms and impairments (3 items); mental

41 and emotional health symptoms and impairments (11 items); uncertainty (14 items); difficulties

42 with day-to-day activities (9 items) and challenges to social inclusion (12 items). We developed

43 a measurement model to test these hypotheses. We used maximum likelihood methods of

44 estimation to determine model fit. We considered a threshold for the Root Mean Square Error of

45 Approximation (RMSEA) of <0.05 as an indication of overall goodness of model fit. We

46 considered variables with factor loadings of >0.30 as representing a given domain of disability.

47 **Setting**: We recruited adults with HIV from hospital clinics, AIDS service organizations and a

48 specialty hospital in Ontario.

49 **Participants**: Of the 361 adults with HIV who completed the HDQ, 80% were men, 36% were

50 50 or older, and 77% reported living with at least two concurrent health conditions in addition to

51 HIV.

52 **Outcome Measures:** We administered the HDQ followed by a demographic questionnaire.

53　**Results**: The model achieved good overall fit as indicated by a RMSEA of 0.030 (90%

54　confidence interval: 0.028-0.033). All HDQ items represented our hypothesized dimensions of

55　disability (factor loadings >0.30). Factor loadings ranged from 0.34 to 0.90. Domains of

56　disability correlated with each other ranging from r =0.47 (between difficulties with day-to-day

57　activities and uncertainty) to r =0.88 (between mental-emotional health challenges and

58　challenges to social inclusion).

59　**Conclusion**: The six domain structure of the HDQ demonstrated construct validity when

60　administered to adults living with HIV.

61

62 **Strengths and Limitations of this Study**

63 ▪ We assessed the construct validity of the HIV Disability Questionnaire (HDQ), a 69 item

64 self-reported questionnaire developed to assess the presence, severity and episodic nature of

65 disability experienced by adults living with HIV.

66 ▪ We conducted a confirmatory factor analysis hypothesizing that domains in the HDQ

67 represented six dimensions of disability, each represented by HDQ items: physical symptoms

68 and impairments (represented by 20 items); cognitive symptoms and impairments (3 items);

69 mental and emotional health symptoms and impairments (11 items); uncertainty (14 items);

70 difficulties with day-to-day activities (9 items) and challenges to social inclusion (12 items).

71 ▪ The six domain structure of the HDQ demonstrated construct validity when administered to

72 adults living with HIV. The hypothesized model achieved good overall fit as indicated by a

73 RMSEA of 0.030. All HDQ items represented our hypothesized dimensions of disability

74 (factor loadings >0.30).

75 ▪ The HDQ is the first known HIV-specific instrument of disability developed from the

76 perspective of adults living with HIV.

77 ▪ The HDQ can be used to help describe the multi-dimensional nature of disability experienced

78 by adults living with HIV and lay the foundation for HIV disability measurement in clinical

79 practice and research.

80

81 **INTRODUCTION**

82 As people living with Human Immunodeficiency Virus (HIV) infection are living longer and

83 aging, they are experiencing the complex health-related challenges of the infection, associated

84 comorbidities, and potential adverse effects of treatment [1-3]. Health related challenges,

85 collectively termed disability, can include symptoms and impairments (e.g. fatigue,

86 neurocognitive impairments, weakness, pain), difficulties with day-to-day activities (e.g.

87 household chores), challenges to social inclusion (e.g. ability to work) and uncertainty or

88 worrying about the future [4-6]. Disability may be experienced as episodic in nature, whereby

89 health challenges fluctuate on a daily basis and over the entire course living with HIV [7]. Given

90 current treatments for HIV and the long-term survival for successfully treated individuals,

91 measuring disability is critical for determining the impact of the disease, its comorbidities and its

92 interventions.

93 We developed a new self-administered instrument, called the HIV Disability

94 Questionnaire (HDQ) using the *Episodic Disability Framework*, a conceptual framework that

95 describes disability experienced by adults living with HIV. The *Episodic Disability Framework*

96 consists of three main components: 1) dimensions of disability that may fluctuate on a daily basis

97 and over the entire course of living with HIV (symptoms and impairments, uncertainty,

98 difficulties with day-to-day activities, and challenges to social inclusion), 2) contextual factors

99 (social support, stigma, living strategies and personal attributes) that may exacerbate or alleviate

100 the dimensions of disability, and 3) triggers, defined as life events that mark momentous or

101 major episodes of disability [7, 8]. The purpose of the HDQ is to describe the presence, severity

102 and episodic nature of disability experienced by adults living with HIV [9]. Items in the HDQ

103 were derived from the *Episodic Disability Framework* [7]. The HDQ consists of six domains of

104   disability: physical symptoms and impairments; cognitive symptoms and impairments; mental

105   and emotional health symptoms and impairments; uncertainty; difficulties with day-to-day

106   activities and challenges to social inclusion [10]. The HDQ possesses sensibility (face and

107   content validity and ease of use) [11]. Our aim was to assess the construct validity of the HDQ

108   among adults living with HIV.

109   **METHODS**

110   We conducted a cross-sectional study to assess the construct validity of the HDQ. We recruited

111   adults (18 years and older) living with HIV from hospital clinics, AIDS service organizations

112   and a specialty hospital in southern Ontario. We administered the HIV Disability Questionnaire

113   (HDQ), followed by a demographic questionnaire. All aspects of this project were conducted in

114   collaboration with a Community Advisory Committee comprised of four members including

115   adults living with HIV, representatives from AIDS Service Organizations and a representative

116   from the Ontario Ministry of Health and Long-Term Care. This research was approved by

117   Research Ethics Boards at McMaster University, Hamilton, Ontario and St. Michael's Hospital,

118   Toronto, Ontario, Canada.

119   **HIV Disability Questionnaire**

120   The HDQ consists of 69 items that describe the presence, severity and episodic nature of

121   disability experienced by adults living with HIV. Each item consists of a statement about a

122   health-related challenge (for example, "I have trouble remembering things like appointments and

123   when to take my medications") and has both a seven point ordinal response scale asking the

124   respondent to rate the challenge on the day of administration (from 0 –'None at all' to 6 –

6

125 'Extreme trouble') and a nominal response scale asking whether the challenge fluctuated (or

126 changed) over the past week ('Yes' or 'No').

127 All data were entered into a database and 20% of cases were independently checked for

128 accuracy. We removed any cases with >10% of item responses missing. We calculated disability

129 presence, severity and episodic scores for each domain and for the total HDQ scale. Disability

130 presence scores were calculated by summing the number of challenges (>1 response option on

131 the seven point scale) for a total disability presence score (ranging from 0-69). Disability severity

132 scores were calculated by summing individual item scores (ranging from 0 to 5) for each domain.

133 Disability episodic scores were calculated by summing the number of challenges identified as

134 episodic ('Yes' responses) (ranging from 0-69). All presence, severity and episodic scores were

135 linearly transformed to a score ranging from 0 to 100. Higher scores on each scale indicated a

136 greater degree or episodic nature of disability.

137 **Analysis**

138 We conducted a confirmatory factor analysis to assess the construct validity of the domains of

139 disability in the HDQ. We hypothesized that domains in the HDQ represented six dimensions of

140 disability, each represented by the following HDQ items: physical symptoms and impairments

141 (represented by 20 items); cognitive symptoms and impairments (3 items); mental and emotional

142 health symptoms and impairments (11 items); uncertainty (14 items); difficulties with day-to-day

143 activities (9 items) and challenges to social inclusion (12 items) (Figure 1).

144 We assessed convergent construct validity by determining the extent to which disability

145 severity scores in the HDQ represented a hypothesized domain of disability with factor loadings

146 >0.30. We assessed divergent construct validity by determining the extent to which domains of

147   disability were distinct constructs that together comprised the larger construct of disability. We

148   considered correlations between latent variables <0.80 as signifying distinct dimensions of

149   disability [12].

150   We used the maximum likelihood methods of estimation, which is preferred for non-

151   normally distributed data [13]. Prior to our analysis, we conducted mean imputation for missing

152   data in order to maximize the sample size for analysis [12]. We estimated and reported

153   standardized parameter estimates (or factor loadings) for each item. We defined factor loadings

154   >0.30 as indicating a relationship between an HDQ item and a given domain; these items were

155   considered as 'loading' on that domain.

156   We used a combination of approaches to evaluate the overall goodness of fit of the

157   confirmatory factor analysis solution [12]. If the solution demonstrated adequate goodness of fit

158   we considered this as constituting evidence in favor of construct validity of the domains of the

159   HDQ. We considered a Root Mean Square Error of Approximation (RMSEA) <0.05,

160   Comparative Fit Index (CFI) >0.95, and Tucker Lewis Index (TLI) >0.95 to indicate good model

161   fit [14, 15]. We considered the RMSEA as the primary statistic for overall goodness of model fit

162   because it is recommended for confirmatory factor analysis [16]. We reported the chi square

163   statistic ($\chi2$) but did not consider it a determinant of model fit given its sensitivity to large

164   sample sizes, which can overestimate lack of model fit [12].

165   We estimated our sample size using the rule that a minimum of five participants per item

166   are required for factor analysis [17]. With 69 disability severity items in the HDQ, we required at

167   least 345 participants. We used SPSS (version 19.0) for computation of HDQ scores and Mplus

168   (version 7.0) for the confirmatory factor analysis [18, 19].

169 **RESULTS**

170 Three-hundred and sixty-one participants were recruited from AIDS service organizations in

171 Toronto (51%), word of mouth (28%), AIDS service organizations in Hamilton, Niagara and

172 Durham regions (7%), a specialty hospital in Toronto (3%) and hospital clinics in Toronto and

173 other areas of southern, Ontario (3%). The majority of participants were men (80%), the median

174 age was 46 years, most were taking antiretroviral medications (83%), and many (77%) were

175 living with two or more health conditions in addition to HIV (Table 1). The most common self-

176 reported concurrent health conditions included mental health challenges including anxiety and

177 depression (40%), arthritis (27%), osteoporosis or osteopenia (16%) and cardiovascular disease

178 (15%).

179 **Table 1 – Characteristics of Participants (n=361)**

Characteristic	Number (%)
Gender	
Men	289 (80%)
Women	66 (18%)
Transgendered	6 (2%)
Age (median; 1st-3rd quartile)	46 years (40-52 years)
50 years or older	130 (36%)
Year of diagnosis (median; 1st– 3rd quartile)	1998 (1991-2005)
Diagnosed prior to 1996	139 (38%)
Taking antiretroviral therapy	301 (83%)
Nadir CD4 count (<200 cells/mm^3)	167 (46%)
Undetectable Viral Load	196 (76%)
Earning between $10,000-20,000 CAN per year	192 (53%)
Currently working for pay	72 (20%)

Living alone	227 (63%)
Have Children	117 (32%)
Live with children	26/117 (22%)
Self-Rated Health Status	
Poor	22 (6%)
Fair	75 (21%)
Good	138 (38%)
Very Good	82 (23%)
Excellent	42 (12%)
Two or more concurrent health conditions	279 (77%)
Common Concurrent Health Conditions	
Mental Health	143 (40%)
Arthritis	97 (27%)
Osteoporosis or Osteopenia	59 (16%)
Cardiovascular Disease (e.g. heart attack or stroke)	55 (15%)
Hepatitis C	51 (14%)
Cancer	40 (11%)
Diabetes	39 (11%)
Neurocognitive Decline	36 (10%)
Liver Disease	36 (10%)

Not all characteristics will add to the total n due to missing responses.

180

181 **HIV Disability Questionnaire**

182 Participants took a median of 14 minutes to complete the HDQ (1st-3rd quartile: 10-20 minutes).

183 Almost all HDQ items (n=66) demonstrated a floor effect with >15% of responses rated '0'

184 indicating no disability. Floor effects were most common in items that referred to symptoms and

185 impairments or difficulties with day-to-day activities. Ten HDQ items demonstrated a ceiling

186 effect with >15% of responses rated '6' indicating the highest severity of disability. Ceiling

187   effects were most common in items pertaining to uncertainty or worrying about the future.

188   Missing responses were <5% across all HDQ disability and episodic items.

189   Median HDQ presence scores (ranging from 0 to 100) ranged from 44 in the difficulties

190   with day-to-day activities domain (1st-3rd quartile: 11-78) to 100 in the cognitive health

191   challenges domain (1st-3rd quartile: 67-100). Median HDQ severity scores were highest in the

192   uncertainty domain (45; 1st-3rd quartile: 27-67) followed by challenges to social inclusion (33;

193   18-51), cognitive (28; 11-50), mental-emotional (27; 14-53) and physical symptoms and

194   impairments (25; 14-38). Median HDQ episodic scores (number of challenges that fluctuated

195   within the week) were greatest in the physical (35; 8-54) and cognitive symptoms and

196   impairments domains (33; 0-67) followed by the mental-emotional symptoms and impairments

197   domain (18; 0-64), difficulties with day-to-day activities (11; 0-33), uncertainty (7; 0-50), and

198   challenges to social inclusion (0; 0-33). The most common health challenges that were reported

199   as episodic spanned the physical and mental-emotional symptoms and impairments and included

200   fatigue (50%), feeling sad, down or depressed (48%), aches and pains (46%), headaches (42%),

201   feeling anxious (41%), having trouble sleeping (40%), and feeling weakness in muscles (40%).

202   Eighty-two percent of participants completed the HDQ on what they considered a 'good day'

203   living with HIV.

Confirmatory Factor Analysis Results

205   Results of the confirmatory factor analysis are presented in Table 2. Correlation matrices are

206   available on request. The RMSEA was 0.030 (90% confidence interval: 0.028-0.033), satisfying

207   our primary goodness of fit criterion. The χ2 value was 3020.981 (p<0.001). Comparative Fit

208   Index (CFI) (0.812) and TLI (0.805) statistics did not meet our pre-specified criteria for

209   goodness of fit. All HDQ items represented our hypothesized domains of disability (factor

210   loadings >0.30). To interpret the first factor loading in Table 2, one standard deviation increase

211   in physical symptoms and impairments is associated with a 0.64 standard deviation increase in

212   loss of energy. Equivalently, the value of the Pearson correlation coefficient between loss of

213   energy and physical symptoms and impairments is 0.64.

214
215

Table 2 - Confirmatory Factor Analysis Results - Domains of Disability in the HIV Disability Questionnaire (HDQ) (n=361)

Domain of Disability (Latent Variables)	Item #	HDQ Items (Indicator Variables)	Standardized Factor Loadings	95% Confidence Interval
Physical Symptoms and Impairments (20 items)	1	I feel too tired to do my usual activities	0.64	0.59-0.70
	2	I have diarrhea	0.34	0.25-0.42
	3	I feel nauseous	0.66	0.60-0.71
	4	I have headaches	0.60	0.54-0.67
	5	I have numbness or tingling in my hands	0.60	0.54-0.67
	6	I have numbness or tingling in my feet	0.58	0.52-0.64
	7	I have aches or pains	0.68	0.64-0.73
	8	I have trouble swallowing food	0.52	0.44-0.59
	9	I have less desire to have sex (decreased libido)	0.46	0.39-0.53
	10	I have shortness of breath	0.59	0.53-0.66
	11	I have fever, chills or sweats	0.57	0.50-0.64
	12	I feel weakness in my muscles	0.73	0.69-0.78
	13	I have muscle cramps	0.67	0.62-0.72
	14	I have stomach cramps	0.63	0.57-0.69
	15	I am losing weight	0.42	0.34-0.50
	16	I lack an appetite for food	0.46	0.39-0.53
	17	I have trouble sleeping	0.50	0.43-0.57
	18	I have problems with my vision	0.57	0.50-0.64
	19	I have problems with my hearing	0.42	0.34-0.50
	20	I feel dizzy	0.70	0.65-0.76
Cognitive Symptoms and Impairments (3 items)	21	I have trouble remembering things like appointments and when to take my medication	0.72	0.67-0.78
	22	I have trouble thinking clearly	0.90	0.87-0.92
	23	I have trouble concentrating	0.87	0.84-0.90

Mental Health Symptoms and Impairments (11items)	24	I feel anxious	0.67	0.62-0.71
	25	I feel sad, down, or depressed	0.77	0.73-0.80
	26	I am afraid for my future	0.77	0.74-0.81
	27	I lack confidence around others	0.76	0.72-0.81
	28	I am uncomfortable with how my body looks	0.62	0.57-0.67
	29	I feel isolated even when I'm around others. In other words, I feel that I don't belong	0.81	0.78-0.84
	30	I feel embarrassed around others	0.82	0.79-0.85
	31	I feel guilty	0.76	0.72-0.81
	32	I feel lonely	0.75	0.71-0.79
	33	I feel discouraged about my future life options	0.81	0.78-0.84
	34	I feel 'shut out' by my friends or family	0.66	0.60-0.72
Uncertainty or Worry about the Future (14 items)	35	I worry about my future health living with HIV	0.84	0.81-0.87
	36	I worry about my lab test results such as my CD4 count and viral load	0.76	0.72-0.80
	37	I worry about having a serious illness.	0.86	0.84-0.88
	38	I worry about what the outcome of my next episode of illness might be	0.87	0.85-0.89
	39	I worry about the side effects of HIV treatments	0.70	0.66-0.75
	40	I worry about my income or financial security living with HIV	0.68	0.64-0.72
	41	I worry what might happen to my family and friends if I have an episode of illness.	0.68	0.63-0.73
	42	I worry about being able to remain in the workforce or return to the workforce	0.56	0.50-0.62
	43	I worry about dying	0.64	0.58-0.70
	44	I worry about my bodily appearance	0.67	0.62-0.71
	45	I worry about the legal issues of telling others about my HIV status	0.58	0.52-0.63
	46	I worry about what others would think of me if they knew I was HIV positive	0.59	0.54-0.64

	47	I worry about transmitting HIV to others	0.39	0.31-0.46
	48	I have put certain life decisions on hold (such as buying a house, returning to work or school, or starting a family) because of my uncertainty living with HIV	0.58	0.53-0.64
Difficulties with Day-to-Day Activities (9 items)	49	I am unsteady on my feet	0.69	0.64-0.74
	50	I have trouble walking	0.75	0.70-0.79
	51	I have trouble climbing stairs	0.73	0.69-0.77
	52	I have trouble with daily activities such as eating, bathing, grooming, or dressing	0.71	0.66-0.77
	53	I have trouble doing household chores such as cleaning, doing dishes, laundry, and cooking	0.78	0.74-0.82
	54	I have trouble taking part in leisure or recreation, such as exercise or dancing	0.78	0.74-0.82
	55	I have trouble getting out to do errands such as grocery shopping, banking, or doctor's appointments	0.85	0.82-0.88
	56	I have trouble keeping track of my finances	0.53	0.47-0.60
	57	I have trouble getting around, such as driving or taking public transportation	0.74	0.68-0.79
Challenges to Social Inclusion (12 items)	58	I find it hard to meet the needs of those I care for (such as children, parents, grandparents, partners, or pets)	0.59	0.52-0.66
	59	I find it hard to fulfill my role as a family or community member living with HIV	0.72	0.68-0.76
	60	I feel cut off from my friends, networks, ethnic or religious communities	0.71	0.66-0.76
	61	My illness prevents me from doing volunteer or paid work or going to school	0.60	0.54-0.66
	62	I feel that my work performance is limited because of my illness	0.64	0.59-0.70
	63	I struggle to maintain safe and stable housing living with HIV	0.48	0.41-0.56

	64	I find it hard to talk with others about my illness, even my family and friends	0.56	0.51-0.62
	65	I find it hard to ask others for help when I go through an episode of illness	0.67	0.62-0.72
	66	I find it hard to start new friendships living with HIV	0.70	0.66-0.75
	67	I find it hard to start new, intimate, sexual relationships living with HIV	0.54	0.48-0.60
	68	I tend to isolate myself from others because I am HIV positive	0.76	0.72-0.80
	69	I find it hard to take part in leisure or recreational things like going to the movies, out to dinner, or on vacation because I can't afford it	0.48	0.41-0.55

216 **Confirmatory Factor Analysis – Goodness of Fit**
217 χ^2 = Chi-square (χ^2)=3020.981 (p value<0.0001)
218 Degrees of freedom (df) =2262;
219 Comparative Fit Index (CFI) =0.812 (ideal is $\geq$0.90)
220 Tucker-Lewis Index (TLI) =0.805 (ideal is$\geq$0.90)
221 Root Mean Square Error of Approximation (RMSEA) =0.030 (good fit indicated by <0.05)
222 **Results**
223 All standardized factor loadings were statistically significant (p<0.0001);
224 All factor loadings were >0.30 which indicate the variables 'load' on a given domain of disability.
225

226　　　　　Factor loadings ranged from 0.34 (item 2: 'I have diarrhea', loading on the physical

227　symptoms and impairments domain) to 0.90 (item 22: 'I have trouble thinking clearly', loading

228　on the cognitive symptoms and impairments domain). Domains of disability correlated with each

229　other ranging from r=0.47 (between difficulties with day-to-day activities and uncertainty) to

230　r=0.88 (between mental-emotional symptoms and impairments and challenges to social

231　inclusion) (Table 3).

232　**Table 3 – Correlations Between Domains in the HIV Disability Questionnaire (HDQ)**
233

HDQ Domain of Disability	HDQ Domain Correlated with…	Factor Loading (Correlation) (Range 0-1)
Cognitive Symptoms and Impairments	Physical	0.70
Mental-Emotional Symptoms and Impairments	Physical	0.64
	Cognition	0.65
Uncertainty	Physical	0.57
	Cognition	0.51
	Mental-Emotional	0.78
Difficulties with Day-to-Day Activities	Physical	0.80
	Cognition	0.59
	Mental-Emotional	0.55
	Uncertainty	0.47
Challenges to Social Inclusion	Physical	0.68
	Cognition	0.64
	Mental-Emotional	0.88
	Uncertainty	0.79
	Day	0.67

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237 **DISCUSSION**

238 This is the first study to assess the construct validity of the HIV Disability Questionnaire, the

239 only HIV-specific measure of disability. Results of our confirmatory factor analysis

240 demonstrated good overall model fit of items with the domain structure, supporting the validity

241 of the six domains of disability in the HDQ.

242   Floor and ceiling effects were evident across the HDQ. We believe that the ceiling effect,

243 primarily seen in items that addressed day-to-day activities, likely reflected the way in which

244 participants were sampled; most were living independently in the community and faced few

245 challenges to mobility or self-care activities. Ceiling effects, with associated severe skewness of

246 item scores, may deflate standard correlation coefficients [20] and lead to an underestimation of

247 factor loadings. While all items loaded significantly on their hypothesized domain of disability

248 (factor loadings > 0.30), the factor loadings might be higher if item response scales were less

249 skewed.

250   Correlations between the latent variables ranged from r=0.47 to r=0.88 (Table 3). A high

251 correlation between mental-emotional challenges and challenges to social inclusion (r =0.88)

252 suggested that these latent variables may not be empirically distinct [12]. However, these

253 domains of disability were represented by items with similar wording, such as 'I feel….'

254 (mental-emotional domain) and 'I find it hard to….' (social inclusion domain) which could

255 explain the high correlation and obscure the discriminant nature between these two domains.

256 Hence, we concluded six domains of the HDQ represent the dimensions that comprise the larger

257 construct of disability.

258   The prevalence of disability including physical impairments, activity limitations, and

259   social participation restrictions among people living with HIV have been documented using

260   measures based on the International Classification of Functioning, Disability and Health (ICF)

261   [1, 5, 6, 21]. The ICF (and the measures derived from the ICF) do not take into account the

262   domain of uncertainty, nor the episodic nature of HIV. The HDQ was developed from the

263   *Episodic Disability Framework*, a conceptual framework specifically derived from the

264   perspective of adults living with HIV [7, 8]. Results showed the highest median HDQ severity

265   score was in the uncertainty domain, highlighting the importance of uncertainty as a key

266   component of disability for adults living with HIV.

267   The highest median HDQ presence score was in the cognitive symptoms and impairments

268   domain. In other studies, self-reported cognitive symptoms have been associated with depression

269   [22]. We confirmed this association in our analysis; the correlation between cognitive and

270   mental-emotional domains was 0.65. While subjectively measured components of mental health

271   correlate with each other, treatment strategies to address mental-emotional and cognitive health

272   symptoms can differ, suggesting these are distinct clinical concepts [23, 24] as represented in the

273   HDQ.

274   Compared with other HDQ domains, symptoms and impairments tended to fluctuate

275   more on a daily basis with median HDQ episodic scores greatest in the physical (35 challenges

276   that fluctuated within the week) cognitive (33 challenges), and mental-emotional (18 challenges)

277   symptoms and impairments domains, demonstrating the potential episodic nature of disability.

278   This was expected given items related to symptoms and impairments such as fatigue, weakness

279   and trouble concentrating may fluctuate more readily than those associated with social inclusion

280   such as the ability to engage or re-engage in the workforce. Specific symptoms and impairments

281 that fluctuated the most included fatigue, feeling sad, down or depressed, aches and pains,

282 headaches, feeling anxious, having trouble sleeping, and feeling weakness in muscles. Despite

283 low episodic domain scores, participants demonstrated a range of episodic health challenges. Our

284 analysis focused on domains of the disability severity scale of the HDQ. Further work is needed

285 to assess the properties of the episodic scale of the HDQ.

286 Lastly, the majority of participants (82%) reported completing the HDQ on a 'good day'

287 living with HIV despite the presence and severity of disability reported in the HDQ. This may be

288 a reflection of resiliency, adaptation and hardiness among people living with HIV [25].

289 Nevertheless, it is unclear how participants in the sample defined a 'good day' versus a 'bad day'

290 living with HIV. Further work exploring the interpretation of this item as it relates to the HDQ

291 disability scores is needed.

292 **Implications for Practice, Research and Policy**

293 The HDQ is the first known HIV-specific disability questionnaire developed to assess the multi-

294 dimensional nature of disability experienced by adults living with HIV. The HDQ has the

295 potential to be used in clinical research and practice. Patient reported outcome measures are

296 important for their ability to detect disability, monitor disease progression, and facilitate patient-

297 clinician communication [26]. Further psychometric assessment including test-retest reliability,

298 interpretability and responsiveness, will enable researchers to use the HDQ to document the

299 presence, severity and episodic nature of disability experienced by adults living with HIV. The

300 HDQ may be considered for use by clinicians and AIDS service organizations to assess the

301 profile of disability experienced by their clients. This may help to identify areas to implement

302 programs, services and interventions to reduce disability experienced by clients with HIV.

303   Strengths of our analytical approach included our adherence to the COSMIN guidelines

304 for assessing validity and hypothesis testing, such as providing a clear description of the a priori

305 hypothesized measurement model and goodness of fit criteria; providing details on the

306 distribution of HDQ scores and missingness sample; and describing the correlations between

307 domains [27, 28].

308   Our study has limitations. First, the HDQ was developed and validated primarily with

309 men in their 40s who were taking antiretroviral therapy, living with concurrent health conditions,

310 and not currently working. Generalizability of these findings to the other people living with HIV

311 has not yet been demonstrated. Similarly, the validity of the HDQ in other cultural and

312 developmental contexts is unknown. Second, our goal was to validate the domain structure of the

313 HDQ (not to measure disability) so HDQ scores should be interpreted cautiously. Third, our a

314 priori goodness of fit criteria only was met for the RMSEA. We considered the RMSEA as the

315 primary statistic for overall goodness of model fit because it is recommended for confirmatory

316 factor analysis [16]. Fourth, while our results indicate that dimensions of disability are correlated

317 to comprise the larger construct of disability, the direct relationships between the domains of

318 disability in the HDQ are unknown. Our results provide a measurement model which can serve

319 as the foundation for future structural equation model analyses to determine the relationships

320 between the domains of disability.

321   Our analysis focused on assessing the construct validity of the domains of the disability

322 scale of the HDQ. Future research will assess the test-retest reliability, interpretability, and

323 responsiveness of the HDQ. Additionally, we will consider the measurement properties of the

324 episodic scale. Longitudinally exploring the episodic nature of disability experienced by adults

325 living with HIV is important from the perspective of people living with HIV.

326 **CONCLUSIONS**

327 Results from this confirmatory factor analysis support the validity of the domains of disability in

328 the HDQ when administered to adults living with HIV in Ontario. This is the first known HIV-

329 specific instrument of disability developed from the perspective of adults living with HIV. The

330 HDQ can be used to help describe the multi-dimensional nature of disability experienced by

331 adults living with HIV and lay the foundation for a future HIV disability measure used in clinical

332 practice and research.

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366 **AUTHORS' CONTRIBUTIONS**

367 KKO led the conceptual design of the study, acquisition of funding, conducted the analysis, and

368 drafted the manuscript. AB and PS participated in the conceptual design of the study, acquisition

369 of funding, analytical interpretations and drafting the manuscript. All authors read and approved

370 the final manuscript.

371 **COMPETING INTERESTS**

372 The authors have no competing interests to declare.

373 **DATA SHARING STATEMENT**

374 Additional data related to the HDQ study is available upon request. The research team will

375 review requests for additional data and in collaboration with the institutional research ethics

376 boards.

377 **FIGURE LEGENDS**

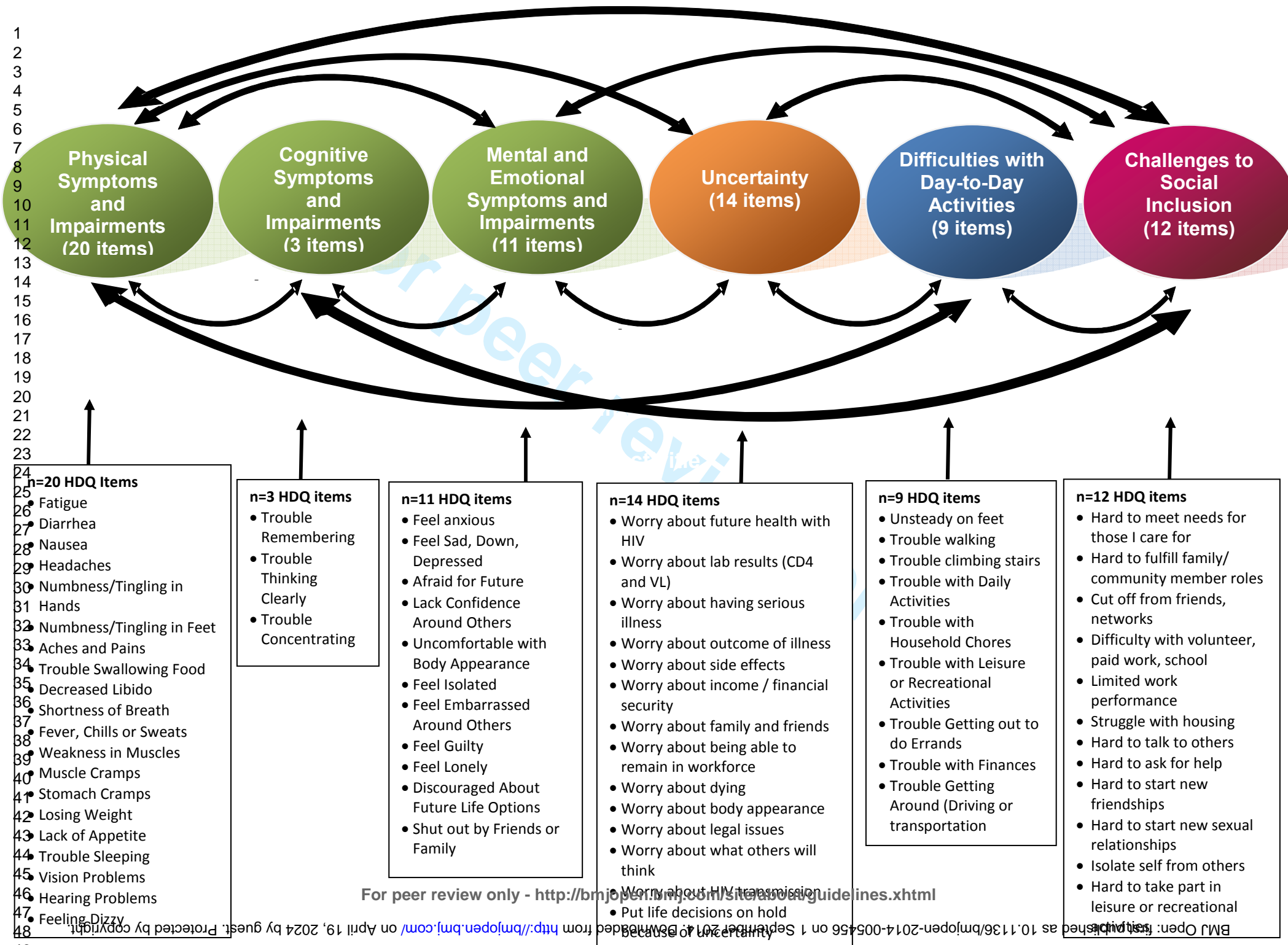378 **Figure 1:** *A priori* Measurement Model for Confirmatory Factor Analysis of the HIV Disability

379 Questionnaire

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1219-1221, 1223-1204.

Figure 1: *A priori* Measurement Model for Confirmatory Factor Analysis of HIV Disability Questionnaire

n=20 HDQ Items
- Fatigue
- Diarrhea
- Nausea
- Headaches
- Numbness/Tingling in Hands
- Numbness/Tingling in Feet
- Aches and Pains
- Trouble Swallowing Food
- Decreased Libido
- Shortness of Breath
- Fever, Chills or Sweats
- Weakness in Muscles
- Muscle Cramps
- Stomach Cramps
- Losing Weight
- Lack of Appetite
- Trouble Sleeping
- Vision Problems
- Hearing Problems
- Feeling Dizzy

n=3 HDQ items
- Trouble Remembering
- Trouble Thinking Clearly
- Trouble Concentrating

n=11 HDQ items
- Feel anxious
- Feel Sad, Down, Depressed
- Afraid for Future
- Lack Confidence Around Others
- Uncomfortable with Body Appearance
- Feel Isolated
- Feel Embarrassed Around Others
- Feel Guilty
- Feel Lonely
- Discouraged About Future Life Options
- Shut out by Friends or Family

n=14 HDQ items
- Worry about future health with HIV
- Worry about lab results (CD4 and VL)
- Worry about having serious illness
- Worry about outcome of illness
- Worry about side effects
- Worry about income / financial security
- Worry about family and friends
- Worry about being able to remain in workforce
- Worry about dying
- Worry about body appearance
- Worry about legal issues
- Worry about what others will think
- Worry about HIV transmission
- Put life decisions on hold because of uncertainty

n=9 HDQ items
- Unsteady on feet
- Trouble walking
- Trouble climbing stairs
- Trouble with Daily Activities
- Trouble with Household Chores
- Trouble with Leisure or Recreational Activities
- Trouble Getting out to do Errands
- Trouble with Finances
- Trouble Getting Around (Driving or transportation

n=12 HDQ items
- Hard to meet needs for those I care for
- Hard to fulfill family/ community member roles
- Cut off from friends, networks
- Difficulty with volunteer, paid work, school
- Limited work performance
- Struggle with housing
- Hard to talk to others
- Hard to ask for help
- Hard to start new friendships
- Hard to start new sexual relationships
- Isolate self from others
- Hard to take part in leisure or recreational activities

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Measuring Disability Experienced by Adults Living with HIV: Assessing Construct Validity of the HIV Disability Questionnaire using Confirmatory Factor Analysis

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1   **Measuring Disability Experienced by Adults Living with HIV: Assessing Construct**

2   **Validity of the HIV Disability Questionnaire using Confirmatory Factor Analysis**

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29   **Key words**: HIV/AIDS; disability; questionnaire; validity; factor analysis

30

31   **Measuring Disability Experienced by Adults Living with HIV: Assessing Construct**

32   **Validity of the HIV Disability Questionnaire using Confirmatory Factor Analysis**

33   **ABSTRACT**

34   **Objectives**: To assess the construct validity of the HIV Disability Questionnaire (HDQ), a self-

35   administered questionnaire that describes the presence, severity and episodic nature of disability

36   experienced by people living with HIV.

37   **Design**: We conducted a confirmatory factor analysis. We hypothesized that domains in the

38   HDQ characterized six dimensions of disability, each represented by HDQ items: physical

39   symptoms and impairments (20 items); cognitive symptoms and impairments (3 items); mental

40   and emotional health symptoms and impairments (11 items); uncertainty (14 items); difficulties

41   with day-to-day activities (9 items) and challenges to social inclusion (12 items).   We developed

42   a measurement model to test these hypotheses. We used maximum likelihood methods of

43   estimation to determine model fit. We considered a threshold for the Root Mean Square Error of

44   Approximation (RMSEA) of <0.05 as an indication of overall goodness of model fit. We

45   considered variables with factor loadings of >0.30 as representing a given domain of disability.

46   **Setting**: We recruited adults with HIV from hospital clinics, AIDS service organizations and a

47   specialty hospital in Ontario.

48   **Participants**: Of the 361 adults with HIV who completed the HDQ, 80% were men, 36% were

49   50 or older, and 77% reported living with at least two concurrent health conditions in addition to

50   HIV.

51   **Outcome Measures:** We administered the HDQ followed by a demographic questionnaire.

52   **Results**: The model achieved good overall fit as indicated by a RMSEA of 0.030 (90%

53   confidence interval: 0.028-0.033). All HDQ items represented our hypothesized dimensions of

54   disability (factor loadings >0.30). Factor loadings ranged from 0.34 to 0.90. Domains of

55   disability correlated with each other ranging from r =0.47 (between difficulties with day-to-day

56   activities and uncertainty) to r =0.88 (between mental-emotional health challenges and

57   challenges to social inclusion).

58   **Conclusion**: The six domain structure of the HDQ demonstrated construct validity when

59   administered to adults living with HIV.

60

61 **Strengths and Limitations of this Study**

62 ▪ We assessed the construct validity of the HIV Disability Questionnaire (HDQ), a 69 item

63 self-reported questionnaire developed to assess the presence, severity and episodic nature of

64 disability experienced by adults living with HIV.

65 ▪ We conducted a confirmatory factor analysis hypothesizing that domains in the HDQ

66 represented six dimensions of disability, each represented by HDQ items: physical symptoms

67 and impairments (represented by 20 items); cognitive symptoms and impairments (3 items);

68 mental and emotional health symptoms and impairments (11 items); uncertainty (14 items);

69 difficulties with day-to-day activities (9 items) and challenges to social inclusion (12 items).

70 ▪ The six domain structure of the HDQ demonstrated construct validity when administered to

71 adults living with HIV. The hypothesized model achieved good overall fit as indicated by a

72 RMSEA of 0.030. All HDQ items represented our hypothesized dimensions of disability

73 (factor loadings >0.30).

74 ▪ The HDQ is the first known HIV-specific instrument of disability developed from the

75 perspective of adults living with HIV.

76 ▪ The HDQ can be used to describe the multi-dimensional nature of disability experienced by

77 adults living with HIV and lay the foundation for more widespread measurement of disability

78 in HIV clinical practice and research.

79

80 **INTRODUCTION**

81 As people living with Human Immunodeficiency Virus (HIV) infection are living longer and

82 aging, they are experiencing the complex health-related challenges of the infection, associated

83 comorbidities, and potential adverse effects of treatment [1-3]. Health related challenges,

84 collectively termed disability, can include symptoms and impairments (e.g. fatigue,

85 neurocognitive impairments, weakness, pain), difficulties with day-to-day activities (e.g.

86 household chores), challenges to social inclusion (e.g. ability to work) and uncertainty or

87 worrying about the future [4-6]. Disability may be experienced as episodic in nature, whereby

88 health challenges fluctuate on a daily basis and over the entire course living with HIV [7]. Given

89 current treatments for HIV and the long-term survival for successfully treated individuals,

90 measuring disability is critical for determining the impact of the disease, its comorbidities and its

91 interventions.

92 We developed a new self-administered instrument, called the HIV Disability

93 Questionnaire (HDQ) using the *Episodic Disability Framework*, a conceptual framework that

94 describes disability experienced by adults living with HIV. The *Episodic Disability Framework*

95 consists of three main components: 1) dimensions of disability that may fluctuate on a daily basis

96 and over the entire course of living with HIV (symptoms and impairments, uncertainty,

97 difficulties with day-to-day activities, and challenges to social inclusion), 2) contextual factors

98 (social support, stigma, living strategies and personal attributes) that may exacerbate or alleviate

99 the dimensions of disability, and 3) triggers, defined as life events that mark momentous or

100 major episodes of disability [7, 8]. The purpose of the HDQ is to describe the presence, severity

101 and episodic nature of disability experienced by adults living with HIV [9]. Items in the HDQ

102 were derived from the *Episodic Disability Framework* [7]. The HDQ consists of six domains of

103 disability: physical symptoms and impairments; cognitive symptoms and impairments; mental

104 and emotional health symptoms and impairments; uncertainty; difficulties with day-to-day

105 activities and challenges to social inclusion [10]. The HDQ possesses sensibility (face and

106 content validity and ease of use) [11]. Our aim was to assess the construct validity of the HDQ

107 among adults living with HIV.

108 **METHODS**

109 We conducted a cross-sectional study to assess the construct validity of the HDQ. We recruited

110 adults (18 years and older) living with HIV by posting recruitment posters and brochures in

111 hospital clinics, AIDS service organizations and a specialty hospital in southern Ontario. Health

112 care providers, who were aware of the study also provided eligible individuals with information

113 about the study and invited them to volunteer to participate. For those who agreed to participate,

114 we administered the HIV Disability Questionnaire (HDQ), followed by a demographic

115 questionnaire. All aspects of this project were conducted in collaboration with a Community

116 Advisory Committee comprised of four members including adults living with HIV,

117 representatives from AIDS Service Organizations and a representative from the Ontario Ministry

118 of Health and Long-Term Care. This research was approved by Research Ethics Boards at

119 McMaster University, Hamilton, Ontario and St. Michael's Hospital, Toronto, Ontario, Canada.

120 **HIV Disability Questionnaire**

121 The HDQ consists of 69 items that describe the presence, severity and episodic nature of

122 disability experienced by adults living with HIV. Each item consists of a statement about a

123 health-related challenge (for example, "I have trouble remembering things like appointments and

124 when to take my medications") and has both a seven point ordinal response scale asking the

125 respondent to rate the challenge on the day of administration (from 0 –'None at all' to 6 –

126 'Extreme trouble') and a nominal response scale asking whether the challenge fluctuated (or

127 changed) over the past week ('Yes' or 'No').

128   All data were entered into a database and 20% of cases were independently checked for

129 accuracy. We removed any cases with >10% of item responses missing. We calculated disability

130 presence, severity and episodic scores for each domain and for the total HDQ scale. Disability

131 presence scores were calculated by summing the number of challenges (>1 response option on

132 the seven point scale) for a total disability presence score (ranging from 0-69). Disability severity

133 scores were calculated by summing individual item scores (ranging from 0 to 5) for each domain.

134 Disability episodic scores were calculated by summing the number of challenges identified as

135 episodic ('Yes' responses) (ranging from 0-69). All presence, severity and episodic scores were

136 linearly transformed to a score ranging from 0 to 100. Higher scores on each scale indicated a

137 greater degree or episodic nature of disability.

138 **Analysis**

139 We conducted a confirmatory factor analysis to assess the construct validity of the domains of

140 disability in the HDQ. We hypothesized that domains in the HDQ represented six dimensions of

141 disability, each represented by the following HDQ items: physical symptoms and impairments

142 (represented by 20 items); cognitive symptoms and impairments (3 items); mental and emotional

143 health symptoms and impairments (11 items); uncertainty (14 items); difficulties with day-to-day

144 activities (9 items) and challenges to social inclusion (12 items) (Figure 1).

145   We assessed convergent construct validity by determining the extent to which disability

146 severity scores in the HDQ represented a hypothesized domain of disability with factor loadings

147 >0.30. We assessed divergent construct validity by determining the extent to which domains of

148 disability were distinct constructs that together comprised the larger construct of disability. We

149 considered correlations between latent variables <0.80 as signifying distinct dimensions of

150 disability [12].

151 We used the maximum likelihood methods of estimation, which is preferred for non-

152 normally distributed data [13]. Prior to our analysis, we conducted mean imputation for missing

153 data in order to maximize the sample size for analysis [12]. We estimated and reported

154 standardized parameter estimates (or factor loadings) for each item. We defined factor loadings

155 >0.30 as indicating a relationship between an HDQ item and a given domain; these items were

156 considered as 'loading' on that domain.

157 We used a combination of approaches to evaluate the overall goodness of fit of the

158 confirmatory factor analysis solution [12]. If the solution demonstrated adequate goodness of fit

159 we considered this as constituting evidence in favor of construct validity of the domains of the

160 HDQ. We considered a Root Mean Square Error of Approximation (RMSEA) <0.05,

161 Comparative Fit Index (CFI) >0.95, and Tucker Lewis Index (TLI) >0.95 to indicate good model

162 fit [14, 15]. The RMSEA is a population-based index that assesses the extent to which a model

163 fits reasonably well in the population by evaluating the discrepancy between the hypothesized

164 model, with optimally chosen parameter estimates, and the population covariance matrix. The

165 RMSEA ranges from 0 to 1, with smaller values indicating better model fit [14, 15]. The CFI

166 and TLI assess model fit by examining the discrepancy between the data and the hypothesized

167 model while adjusting for sample size. Comparative Fit Index (CFI) and TLI values range from

168 0 to 1 with higher values indicating better fit [14, 15]. We considered the RMSEA as the

169 primary statistic for overall goodness of model fit because it is less sensitive to sample size and

170   is recommended for confirmatory factor analysis [16]. We reported the chi square statistic ($\chi2$)

171   but did not consider it a determinant of model fit given its sensitivity to large sample sizes, which

172   can overestimate lack of model fit [12].

173   We estimated our sample size using the rule that a minimum of five participants per item

174   are required for factor analysis [17]. With 69 disability severity items in the HDQ, we required at

175   least 345 participants. We used SPSS (version 19.0) for computation of HDQ scores and Mplus

176   (version 7.0) for the confirmatory factor analysis [18, 19].

177   **RESULTS**

178   Three-hundred and sixty-one participants were recruited from AIDS service organizations in

179   Toronto (51%), word of mouth (28%), AIDS service organizations in Hamilton, Niagara and

180   Durham regions (7%), a specialty hospital in Toronto (3%) and hospital clinics in Toronto and

181   other areas of southern, Ontario (3%). The majority of participants were men (80%), the median

182   age was 46 years, most were taking antiretroviral medications (83%), and many (77%) were

183   living with two or more health conditions in addition to HIV (Table 1). The most common self-

184   reported concurrent health conditions included mental health challenges including anxiety and

185   depression (40%), arthritis (27%), osteoporosis or osteopenia (16%) and cardiovascular disease

186   (15%).

187   **Table 1 – Characteristics of Participants (n=361)**

Characteristic	Number (%)
Gender	
Men	289 (80%)
Women	66 (18%)
Transgendered	6 (2%)

Age (median; 1st-3rd quartile)	46 years (40-52 years)
50 years or older	130 (36%)
Year of diagnosis (median; 1st– 3rd quartile)	1998 (1991-2005)
Diagnosed prior to 1996	139 (38%)
Taking antiretroviral therapy	301 (83%)
Nadir CD4 count (<200 cells/mm^3)	167 (46%)
Undetectable Viral Load	196 (76%)
Earning between $10,000-20,000 CAN per year	192 (53%)
Currently working for pay	72 (20%)
Living alone	227 (63%)
Have Children	117 (32%)
Live with children	26/117 (22%)
Self-Rated Health Status	
Poor	22 (6%)
Fair	75 (21%)
Good	138 (38%)
Very Good	82 (23%)
Excellent	42 (12%)
Two or more concurrent health conditions	279 (77%)
Common Concurrent Health Conditions	
Mental Health	143 (40%)
Arthritis	97 (27%)
Osteoporosis or Osteopenia	59 (16%)
Cardiovascular Disease (e.g. heart attack or stroke)	55 (15%)
Hepatitis C	51 (14%)
Cancer	40 (11%)
Diabetes	39 (11%)
Neurocognitive Decline	36 (10%)
Liver Disease	36 (10%)

Not all characteristics will add to the total n due to missing responses.

188   **HIV Disability Questionnaire**

189   Participants took a median of 14 minutes to complete the HDQ (1st-3rd quartile: 10-20 minutes).

190   Almost all HDQ items (n=66) demonstrated a floor effect with >15% of responses rated '0'

191   indicating no disability. Floor effects were most common in items that referred to symptoms and

192   impairments or difficulties with day-to-day activities. Ten HDQ items demonstrated a ceiling

193   effect with >15% of responses rated '6' indicating the highest severity of disability. Ceiling

194   effects were most common in items pertaining to uncertainty or worrying about the future.

195   Missing responses were <5% across all HDQ disability and episodic items.

196   Median HDQ presence scores (ranging from 0 to 100) ranged from 44 in the difficulties

197   with day-to-day activities domain (1st-3rd quartile: 11-78) to 100 in the cognitive health

198   challenges domain (1st-3rd quartile: 67-100). Median HDQ severity scores were highest in the

199   uncertainty domain (45; 1st-3rd quartile: 27-67) followed by challenges to social inclusion (33;

200   18-51), cognitive (28; 11-50), mental-emotional (27; 14-53) and physical symptoms and

201   impairments (25; 14-38). Median HDQ episodic scores (number of challenges that fluctuated

202   within the week) were greatest in the physical (35; 8-54) and cognitive symptoms and

203   impairments domains (33; 0-67) followed by the mental-emotional symptoms and impairments

204   domain (18; 0-64), difficulties with day-to-day activities (11; 0-33), uncertainty (7; 0-50), and

205   challenges to social inclusion (0; 0-33). The most common health challenges that were reported

206   as episodic spanned the physical and mental-emotional symptoms and impairments and included

207   fatigue (50%), feeling sad, down or depressed (48%), aches and pains (46%), headaches (42%),

208   feeling anxious (41%), having trouble sleeping (40%), and feeling weakness in muscles (40%).

209   Eighty-two percent of participants completed the HDQ on what they considered a 'good day'

210   living with HIV.

211 **Confirmatory Factor Analysis Results**

212 Results of the confirmatory factor analysis are presented in Table 2. Correlation matrices are

213 available on request. The RMSEA was 0.030 (90% confidence interval: 0.028-0.033), satisfying

214 our primary goodness of fit criterion. The $\chi 2$ value was 3020.981 (p<0.001). Comparative Fit

215 Index (CFI) (0.812) and TLI (0.805) statistics did not meet our pre-specified criteria for

216 goodness of fit. All HDQ items represented our hypothesized domains of disability (factor

217 loadings >0.30). To interpret the first factor loading in Table 2, one standard deviation increase

218 in physical symptoms and impairments is associated with a 0.64 standard deviation increase in

219 loss of energy. Equivalently, the value of the Pearson correlation coefficient between loss of

220 energy and physical symptoms and impairments is 0.64.

221
222

Table 2 - Confirmatory Factor Analysis Results - Domains of Disability in the HIV Disability Questionnaire (HDQ) (n=361)

Domain of Disability (Latent Variables)	Item #	HDQ Items (Indicator Variables)	Standardized Factor Loadings	95% Confidence Interval
Physical Symptoms and Impairments (20 items)	1	I feel too tired to do my usual activities	0.64	0.59-0.70
	2	I have diarrhea	0.34	0.25-0.42
	3	I feel nauseous	0.66	0.60-0.71
	4	I have headaches	0.60	0.54-0.67
	5	I have numbness or tingling in my hands	0.60	0.54-0.67
	6	I have numbness or tingling in my feet	0.58	0.52-0.64
	7	I have aches or pains	0.68	0.64-0.73
	8	I have trouble swallowing food	0.52	0.44-0.59
	9	I have less desire to have sex (decreased libido)	0.46	0.39-0.53
	10	I have shortness of breath	0.59	0.53-0.66
	11	I have fever, chills or sweats	0.57	0.50-0.64
	12	I feel weakness in my muscles	0.73	0.69-0.78
	13	I have muscle cramps	0.67	0.62-0.72
	14	I have stomach cramps	0.63	0.57-0.69
	15	I am losing weight	0.42	0.34-0.50
	16	I lack an appetite for food	0.46	0.39-0.53
	17	I have trouble sleeping	0.50	0.43-0.57
	18	I have problems with my vision	0.57	0.50-0.64
	19	I have problems with my hearing	0.42	0.34-0.50
	20	I feel dizzy	0.70	0.65-0.76
Cognitive Symptoms and Impairments (3 items)	21	I have trouble remembering things like appointments and when to take my medication	0.72	0.67-0.78
	22	I have trouble thinking clearly	0.90	0.87-0.92
	23	I have trouble concentrating	0.87	0.84-0.90

Mental Health Symptoms and Impairments (11items)	24	I feel anxious	0.67	0.62-0.71
	25	I feel sad, down, or depressed	0.77	0.73-0.80
	26	I am afraid for my future	0.77	0.74-0.81
	27	I lack confidence around others	0.76	0.72-0.81
	28	I am uncomfortable with how my body looks	0.62	0.57-0.67
	29	I feel isolated even when I'm around others. In other words, I feel that I don't belong	0.81	0.78-0.84
	30	I feel embarrassed around others	0.82	0.79-0.85
	31	I feel guilty	0.76	0.72-0.81
	32	I feel lonely	0.75	0.71-0.79
	33	I feel discouraged about my future life options	0.81	0.78-0.84
	34	I feel 'shut out' by my friends or family	0.66	0.60-0.72
Uncertainty or Worry about the Future (14 items)	35	I worry about my future health living with HIV	0.84	0.81-0.87
	36	I worry about my lab test results such as my CD4 count and viral load	0.76	0.72-0.80
	37	I worry about having a serious illness.	0.86	0.84-0.88
	38	I worry about what the outcome of my next episode of illness might be	0.87	0.85-0.89
	39	I worry about the side effects of HIV treatments	0.70	0.66-0.75
	40	I worry about my income or financial security living with HIV	0.68	0.64-0.72
	41	I worry what might happen to my family and friends if I have an episode of illness.	0.68	0.63-0.73
	42	I worry about being able to remain in the workforce or return to the workforce	0.56	0.50-0.62
	43	I worry about dying	0.64	0.58-0.70
	44	I worry about my bodily appearance	0.67	0.62-0.71
	45	I worry about the legal issues of telling others about my HIV status	0.58	0.52-0.63
	46	I worry about what others would think of me if they knew I was HIV positive	0.59	0.54-0.64

	47	I worry about transmitting HIV to others	0.39	0.31-0.46
	48	I have put certain life decisions on hold (such as buying a house, returning to work or school, or starting a family) because of my uncertainty living with HIV	0.58	0.53-0.64
Difficulties with Day-to-Day Activities (9 items)	49	I am unsteady on my feet	0.69	0.64-0.74
	50	I have trouble walking	0.75	0.70-0.79
	51	I have trouble climbing stairs	0.73	0.69-0.77
	52	I have trouble with daily activities such as eating, bathing, grooming, or dressing	0.71	0.66-0.77
	53	I have trouble doing household chores such as cleaning, doing dishes, laundry, and cooking	0.78	0.74-0.82
	54	I have trouble taking part in leisure or recreation, such as exercise or dancing	0.78	0.74-0.82
	55	I have trouble getting out to do errands such as grocery shopping, banking, or doctor's appointments	0.85	0.82-0.88
	56	I have trouble keeping track of my finances	0.53	0.47-0.60
	57	I have trouble getting around, such as driving or taking public transportation	0.74	0.68-0.79
Challenges to Social Inclusion (12 items)	58	I find it hard to meet the needs of those I care for (such as children, parents, grandparents, partners, or pets)	0.59	0.52-0.66
	59	I find it hard to fulfill my role as a family or community member living with HIV	0.72	0.68-0.76
	60	I feel cut off from my friends, networks, ethnic or religious communities	0.71	0.66-0.76
	61	My illness prevents me from doing volunteer or paid work or going to school	0.60	0.54-0.66
	62	I feel that my work performance is limited because of my illness	0.64	0.59-0.70
	63	I struggle to maintain safe and stable housing living with HIV	0.48	0.41-0.56

	64	I find it hard to talk with others about my illness, even my family and friends	0.56	0.51-0.62
	65	I find it hard to ask others for help when I go through an episode of illness	0.67	0.62-0.72
	66	I find it hard to start new friendships living with HIV	0.70	0.66-0.75
	67	I find it hard to start new, intimate, sexual relationships living with HIV	0.54	0.48-0.60
	68	I tend to isolate myself from others because I am HIV positive	0.76	0.72-0.80
	69	I find it hard to take part in leisure or recreational things like going to the movies, out to dinner, or on vacation because I can't afford it	0.48	0.41-0.55

223 **Confirmatory Factor Analysis – Goodness of Fit**
224 χ^2 = Chi-square (χ^2)=3020.981 (p value<0.0001)
225 Degrees of freedom (df) =2262;
226 Comparative Fit Index (CFI) =0.812 (ideal is $\geq$0.90)
227 Tucker-Lewis Index (TLI) =0.805 (ideal is$\geq$0.90)
228 Root Mean Square Error of Approximation (RMSEA) =0.030 (good fit indicated by <0.05)
229 **Results**
230 All standardized factor loadings were statistically significant (p<0.0001);
231 All factor loadings were >0.30 which indicate the variables 'load' on a given domain of disability.
232

233   Factor loadings ranged from 0.34 (item 2: 'I have diarrhea', loading on the physical

234 symptoms and impairments domain) to 0.90 (item 22: 'I have trouble thinking clearly', loading

235 on the cognitive symptoms and impairments domain). Domains of disability correlated with each

236 other ranging from r=0.47 (between difficulties with day-to-day activities and uncertainty) to

237 r=0.88 (between mental-emotional symptoms and impairments and challenges to social

238 inclusion) (Table 3).

239 **Table 3 – Correlations Between Domains in the HIV Disability Questionnaire (HDQ)**

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HDQ Domain of Disability	HDQ Domain Correlated with…	Factor Loading (Correlation) (Range 0-1)
Cognitive Symptoms and Impairments	Physical	0.70
Mental-Emotional Symptoms and Impairments	Physical	0.64
	Cognition	0.65
Uncertainty	Physical	0.57
	Cognition	0.51
	Mental-Emotional	0.78
Difficulties with Day-to-Day Activities	Physical	0.80
	Cognition	0.59
	Mental-Emotional	0.55
	Uncertainty	0.47
Challenges to Social Inclusion	Physical	0.68
	Cognition	0.64
	Mental-Emotional	0.88
	Uncertainty	0.79
	Day	0.67

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244 **DISCUSSION**

245 This is the first study to assess the construct validity of the HIV Disability Questionnaire, the

246 only HIV-specific measure of disability. Results of our confirmatory factor analysis

247 demonstrated good overall model fit of items with the domain structure, supporting the validity

248 of the six domains of disability in the HDQ.

249   Floor and ceiling effects were evident across the HDQ. We believe that the ceiling effect,

250 primarily seen in items that addressed day-to-day activities, likely reflected the way in which

251 participants were sampled; most were living independently in the community and faced few

252 challenges to mobility or self-care activities. Ceiling effects, with associated severe skewness of

253 item scores, may deflate standard correlation coefficients [20] and lead to an underestimation of

254 factor loadings. While all items loaded significantly on their hypothesized domain of disability

255 (factor loadings > 0.30), the factor loadings might be higher if item response scales were less

256 skewed.

257   Correlations between the latent variables ranged from r=0.47 to r=0.88 (Table 3). A high

258 correlation between mental-emotional challenges and challenges to social inclusion (r =0.88)

259 suggested that these latent variables may not be empirically distinct [12]. However, these

260 domains of disability were represented by items with similar wording, such as 'I feel….'

261 (mental-emotional domain) and 'I find it hard to….' (social inclusion domain) which could

262 explain the high correlation and obscure the discriminant nature between these two domains. The

263 correlation between mental and emotional health challenges and challenges to social inclusion

264 also may reflect the influence of mental health on aspects of social inclusion such as employment

265 among people living with HIV [21, 22]. Overall, we concluded six domains of the HDQ

266   represent the dimensions that comprise the larger construct of disability. Nevertheless, when

267   administering the HDQ, researchers, clinicians and community members should acknowledge

268   the interrelationships between dimensions of disability and the influence dimensions may have

269   on each other when interpreting HDQ domain scores.

270   The prevalence of disability including physical impairments, activity limitations, and

271   social participation restrictions among people living with HIV have been documented using

272   measures based on the International Classification of Functioning, Disability and Health (ICF)

273   [1, 5, 6, 23]. The ICF (and the measures derived from the ICF) do not take into account the

274   domain of uncertainty, nor the episodic nature of HIV. The HDQ was developed from the

275   *Episodic Disability Framework*, a conceptual framework specifically derived and empirically

276   validated with, adults living with HIV [7, 8, 24]. Results showed the highest median HDQ

277   severity score was in the uncertainty domain, highlighting the importance of uncertainty as a key

278   component of disability for adults living with HIV. The *Episodic Disability Framework* also

279   has been used to inform qualitative approaches to exploring experiences of older men who self-

280   identify as having HIV-associated neurocognitive challenges and considered an approach to

281   conceptualize disability among people living with HIV internationally [25, 26]. However, this is

282   the first known study to use the *Episodic Disability Framework* to inform the development and

283   validation of a new quantitative measure of disability for adults living with HIV. With episodic

284   health and disability identified as a key research priority in the HIV and rehabilitation field [27],

285   the HDQ will be integral to accurately and consistently describe the health-related consequences

286   of HIV, aging, and related comorbidities with adults living with HIV.

287   The highest median HDQ presence score was in the cognitive symptoms and impairments

288   domain. In other studies, self-reported cognitive symptoms have been associated with depression

289 [28]. We confirmed this association in our analysis; the correlation between cognitive and

290 mental-emotional domains was 0.65. While subjectively measured components of mental health

291 correlate with each other, treatment strategies to address mental-emotional and cognitive health

292 symptoms can differ, suggesting these are distinct clinical concepts [29, 30] as represented in the

293 HDQ.

294 Compared with other HDQ domains, symptoms and impairments tended to fluctuate

295 more on a daily basis with median HDQ episodic scores greatest in the physical (35 challenges

296 that fluctuated within the week) cognitive (33 challenges), and mental-emotional (18 challenges)

297 symptoms and impairments domains, demonstrating the potential episodic nature of disability.

298 This was expected given items related to symptoms and impairments such as fatigue, weakness

299 and trouble concentrating may fluctuate more readily than those associated with social inclusion

300 such as the ability to engage or re-engage in the workforce. Specific symptoms and impairments

301 that fluctuated the most included fatigue, feeling sad, down or depressed, aches and pains,

302 headaches, feeling anxious, having trouble sleeping, and feeling weakness in muscles. Despite

303 low episodic domain scores, participants demonstrated a range of episodic health challenges. Our

304 analysis focused on domains of the disability severity scale of the HDQ. Further work is needed

305 to assess the properties of the episodic scale of the HDQ.

306 Lastly, the majority of participants (82%) reported completing the HDQ on a 'good day'

307 living with HIV despite the presence and severity of disability reported in the HDQ. This may be

308 a reflection of resiliency, adaptation and hardiness among people living with HIV [31].

309 Nevertheless, it is unclear how participants in the sample defined a 'good day' versus a 'bad day'

310 living with HIV. Further work exploring the interpretation of this item as it relates to the HDQ

311 disability scores is needed.

312   **Implications for Practice, Research and Policy**

313   The HDQ is the first known HIV-specific disability questionnaire developed to assess the multi-

314   dimensional nature of disability experienced by adults living with HIV. The HDQ has the

315   potential to be used in clinical research, practice and policy. Patient reported outcome measures

316   are important for their ability to detect disability, monitor disease progression, and facilitate

317   patient-clinician communication [32]. Further psychometric assessment including test-retest

318   reliability, interpretability and responsiveness, will enable researchers to use the HDQ to

319   document the presence, severity and episodic nature of disability experienced by adults living

320   with HIV. The HDQ may be considered for use by clinicians and AIDS service organizations to

321   assess the profile of disability experienced by their clients. This may help to identify areas to

322   implement programs, services and interventions to reduce disability experienced by clients with

323   HIV. Universal measurement of disability with the HDQ may facilitate more broad and ongoing

324   tracking of episodic disability trends and evaluation of interventions to inform resource

325   allocation, as well as income and employment program and policies to ensure optimal care and

326   social inclusion for people living with HIV.

327   Strengths of our analytical approach included our adherence to the COSMIN guidelines

328   for assessing validity and hypothesis testing, such as providing a clear description of the a priori

329   hypothesized measurement model and goodness of fit criteria; providing details on the

330   distribution of HDQ scores and missingness sample; and describing the correlations between

331   domains [33, 34].

332   Our study has limitations. First, the HDQ was developed and validated primarily with

333   men in their 40s who were taking antiretroviral therapy, living with concurrent health conditions,

334 and not currently working. Generalizability of these findings to the other people living with HIV

335 has not yet been demonstrated. Similarly, the validity of the HDQ in other cultural and

336 developmental contexts is unknown. Second, our goal was to validate the domain structure of the

337 HDQ (not to measure disability) so HDQ scores should be interpreted cautiously. Third, our a

338 priori goodness of fit criteria only was met for the RMSEA. We considered the RMSEA as the

339 primary statistic for overall goodness of model fit because it is recommended for confirmatory

340 factor analysis [16]. Fourth, while our results indicate that dimensions of disability are correlated

341 to comprise the larger construct of disability, the direct relationships between the domains of

342 disability in the HDQ are unknown. Our results provide a measurement model which can serve

343 as the foundation for future structural equation model analyses to determine the relationships

344 between the domains of disability.

345 Our analysis focused on assessing the construct validity of the domains of the disability

346 scale of the HDQ. Future research will assess the test-retest reliability, interpretability, and

347 responsiveness of the HDQ. Additionally, we will consider the measurement properties of the

348 episodic scale. Longitudinally exploring the episodic nature of disability experienced by adults

349 living with HIV is important from the perspective of people living with HIV.

CONCLUSIONS

351 Results from this confirmatory factor analysis support the validity of the domains of disability in

352 the HDQ when administered to adults living with HIV in Ontario. This is the first known HIV-

353 specific instrument of disability developed from the perspective of adults living with HIV. The

354 HDQ can be used to describe the multi-dimensional nature of disability experienced by adults

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355   living with HIV and lay the foundation for more widespread measurement of disability in HIV

356   clinical practice and research.

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373 **FOOTNOTES**

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394   endorsement by supporting agencies is intended or should be inferred.

395   **AUTHORS' CONTRIBUTIONS**

396   KKO led the conceptual design of the study, acquisition of funding, conducted the analysis, and

397   drafted the manuscript. AB and PS participated in the conceptual design of the study, acquisition

398   of funding, analytical interpretations and drafting the manuscript. All authors read and approved

399   the final manuscript.

400   **COMPETING INTERESTS**

401   The authors have no competing interests to declare.

402   **DATA SHARING STATEMENT**

403   No additional data available

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FIGURE LEGENDS

Figure 1: *A priori* Measurement Model for Confirmatory Factor Analysis of the HIV Disability

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1   **Measuring Disability Experienced by Adults Living with HIV: Assessing Construct**

2   **Validity of the HIV Disability Questionnaire using Confirmatory Factor Analysis**

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Measuring Disability Experienced by Adults Living with HIV: Assessing Construct

Validity of the HIV Disability Questionnaire using Confirmatory Factor Analysis

ABSTRACT

Objectives: To assess the construct validity of the HIV Disability Questionnaire (HDQ), a self-administered questionnaire that describes the presence, severity and episodic nature of disability experienced by people living with HIV.

Design: We conducted a confirmatory factor analysis. We hypothesized that domains in the HDQ characterized six dimensions of disability, each represented by HDQ items: physical symptoms and impairments (20 items); cognitive symptoms and impairments (3 items); mental and emotional health symptoms and impairments (11 items); uncertainty (14 items); difficulties with day-to-day activities (9 items) and challenges to social inclusion (12 items). We developed a measurement model to test these hypotheses. We used maximum likelihood methods of estimation to determine model fit. We considered a threshold for the Root Mean Square Error of Approximation (RMSEA) of <0.05 as an indication of overall goodness of model fit. We considered variables with factor loadings of >0.30 as representing a given domain of disability.

Setting: We recruited adults with HIV from hospital clinics, AIDS service organizations and a specialty hospital in Ontario.

Participants: Of the 361 adults with HIV who completed the HDQ, 80% were men, 36% were 50 or older, and 77% reported living with at least two concurrent health conditions in addition to HIV.

Outcome Measures: We administered the HDQ followed by a demographic questionnaire.

2

52   **Results**: The model achieved good overall fit as indicated by a RMSEA of 0.030 (90%

53   confidence interval: 0.028-0.033). All HDQ items represented our hypothesized dimensions of

54   disability (factor loadings >0.30). Factor loadings ranged from 0.34 to 0.90. Domains of

55   disability correlated with each other ranging from r =0.47 (between difficulties with day-to-day

56   activities and uncertainty) to r =0.88 (between mental-emotional health challenges and

57   challenges to social inclusion).

58   **Conclusion**: The six domain structure of the HDQ demonstrated construct validity when

59   administered to adults living with HIV.

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61 **Strengths and Limitations of this Study**

62 ▪ We assessed the construct validity of the HIV Disability Questionnaire (HDQ), a 69 item

63 self-reported questionnaire developed to assess the presence, severity and episodic nature of

64 disability experienced by adults living with HIV.

65 ▪ We conducted a confirmatory factor analysis hypothesizing that domains in the HDQ

66 represented six dimensions of disability, each represented by HDQ items: physical symptoms

67 and impairments (represented by 20 items); cognitive symptoms and impairments (3 items);

68 mental and emotional health symptoms and impairments (11 items); uncertainty (14 items);

69 difficulties with day-to-day activities (9 items) and challenges to social inclusion (12 items).

70 ▪ The six domain structure of the HDQ demonstrated construct validity when administered to

71 adults living with HIV. The hypothesized model achieved good overall fit as indicated by a

72 RMSEA of 0.030. All HDQ items represented our hypothesized dimensions of disability

73 (factor loadings >0.30).

74 ▪ The HDQ is the first known HIV-specific instrument of disability developed from the

75 perspective of adults living with HIV.

76 ▪ The HDQ can be used to ~~help~~ describe the multi-dimensional nature of disability experienced

77 by adults living with HIV and lay the foundation for ~~HIV disability measurement in~~more

78 widespread measurement of disability in HIV clinical practice and research.

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80   **INTRODUCTION**

81   As people living with Human Immunodeficiency Virus (HIV) infection are living longer and

82   aging, they are experiencing the complex health-related challenges of the infection, associated

83   comorbidities, and potential adverse effects of treatment [1-3]. Health related challenges,

84   collectively termed disability, can include symptoms and impairments (e.g. fatigue,

85   neurocognitive impairments, weakness, pain), difficulties with day-to-day activities (e.g.

86   household chores), challenges to social inclusion (e.g. ability to work) and uncertainty or

87   worrying about the future [4-6]. Disability may be experienced as episodic in nature, whereby

88   health challenges fluctuate on a daily basis and over the entire course living with HIV [7]. Given

89   current treatments for HIV and the long-term survival for successfully treated individuals,

90   measuring disability is critical for determining the impact of the disease, its comorbidities and its

91   interventions.

92   We developed a new self-administered instrument, called the HIV Disability

93   Questionnaire (HDQ) using the *Episodic Disability Framework*, a conceptual framework that

94   describes disability experienced by adults living with HIV. The *Episodic Disability Framework*

95   consists of three main components: 1) dimensions of disability that may fluctuate on a daily basis

96   and over the entire course of living with HIV (symptoms and impairments, uncertainty,

97   difficulties with day-to-day activities, and challenges to social inclusion), 2) contextual factors

98   (social support, stigma, living strategies and personal attributes) that may exacerbate or alleviate

99   the dimensions of disability, and 3) triggers, defined as life events that mark momentous or

100 major episodes of disability [7, 8]. The purpose of the HDQ is to describe the presence, severity

101 and episodic nature of disability experienced by adults living with HIV [9]. Items in the HDQ

102 were derived from the *Episodic Disability Framework* [7]. The HDQ consists of six domains of

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103   disability: physical symptoms and impairments; cognitive symptoms and impairments; mental

104   and emotional health symptoms and impairments; uncertainty; difficulties with day-to-day

105   activities and challenges to social inclusion [10]. The HDQ possesses sensibility (face and

106   content validity and ease of use) [11]. Our aim was to assess the construct validity of the HDQ

107   among adults living with HIV.

108   **METHODS**

109   We conducted a cross-sectional study to assess the construct validity of the HDQ. We recruited

110   adults (18 years and older) living with HIV by posting recruitment posters and brochures in from

111   hospital clinics, AIDS service organizations and a specialty hospital in southern Ontario . Health

112   care providers, who were aware of the study also provided eligible individuals with brochure

113   information about the study and invited them to volunteer to participate. For those who agreed

114   to participate, wWe administered the HIV Disability Questionnaire (HDQ), followed by a

115   demographic questionnaire. All aspects of this project were conducted in collaboration with a

116   Community Advisory Committee comprised of four members including adults living with HIV,

117   representatives from AIDS Service Organizations and a representative from the Ontario Ministry

118   of Health and Long-Term Care. This research was approved by Research Ethics Boards at

119   McMaster University, Hamilton, Ontario and St. Michael's Hospital, Toronto, Ontario, Canada.

120   **HIV Disability Questionnaire**

121   The HDQ consists of 69 items that describe the presence, severity and episodic nature of

122   disability experienced by adults living with HIV. Each item consists of a statement about a

123   health-related challenge (for example, "I have trouble remembering things like appointments and

124   when to take my medications") and has both a seven point ordinal response scale asking the

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125 respondent to rate the challenge on the day of administration (from 0 –'None at all' to 6 –

126 'Extreme trouble') and a nominal response scale asking whether the challenge fluctuated (or

127 changed) over the past week ('Yes' or 'No').

128   All data were entered into a database and 20% of cases were independently checked for

129 accuracy. We removed any cases with >10% of item responses missing. We calculated disability

130 presence, severity and episodic scores for each domain and for the total HDQ scale. Disability

131 presence scores were calculated by summing the number of challenges (>1 response option on

132 the seven point scale) for a total disability presence score (ranging from 0-69). Disability severity

133 scores were calculated by summing individual item scores (ranging from 0 to 5) for each domain.

134 Disability episodic scores were calculated by summing the number of challenges identified as

135 episodic ('Yes' responses) (ranging from 0-69). All presence, severity and episodic scores were

136 linearly transformed to a score ranging from 0 to 100. Higher scores on each scale indicated a

137 greater degree or episodic nature of disability.

138 **Analysis**

139 We conducted a confirmatory factor analysis to assess the construct validity of the domains of

140 disability in the HDQ. We hypothesized that domains in the HDQ represented six dimensions of

141 disability, each represented by the following HDQ items: physical symptoms and impairments

142 (represented by 20 items); cognitive symptoms and impairments (3 items); mental and emotional

143 health symptoms and impairments (11 items); uncertainty (14 items); difficulties with day-to-day

144 activities (9 items) and challenges to social inclusion (12 items) (Figure 1).

145   We assessed convergent construct validity by determining the extent to which disability

146 severity scores in the HDQ represented a hypothesized domain of disability with factor loadings

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147 >0.30. We assessed divergent construct validity by determining the extent to which domains of

148 disability were distinct constructs that together comprised the larger construct of disability. We

149 considered correlations between latent variables <0.80 as signifying distinct dimensions of

150 disability [12].

151   We used the maximum likelihood methods of estimation, which is preferred for non-

152 normally distributed data [13]. Prior to our analysis, we conducted mean imputation for missing

153 data in order to maximize the sample size for analysis [12]. We estimated and reported

154 standardized parameter estimates (or factor loadings) for each item. We defined factor loadings

155 >0.30 as indicating a relationship between an HDQ item and a given domain; these items were

156 considered as 'loading' on that domain.

157   We used a combination of approaches to evaluate the overall goodness of fit of the

158 confirmatory factor analysis solution [12]. If the solution demonstrated adequate goodness of fit

159 we considered this as constituting evidence in favor of construct validity of the domains of the

160 HDQ. We considered a Root Mean Square Error of Approximation (RMSEA) <0.05,

161 Comparative Fit Index (CFI) >0.95, and Tucker Lewis Index (TLI) >0.95 to indicate good model

162 fit [14, 15]. The RMSEA is a population-based index that assesses the extent to which a model

163 fits reasonably well in the population by evaluating the discrepancy between the hypothesized

164 model, with optimally chosen parameter estimates, and the population covariance matrix. The

165 RMSEA ranges from 0 to 1, with smaller values indicating better model fit [14, 15]. The CFI

166 and TLI assess model fit by examining the discrepancy between the data and the hypothesized

167 model while adjusting for sample size. Comparative Fit Index (CFI) and TLI values range from

168 0 to 1 with higher values indicating better fit [14, 15]. We considered the RMSEA as the

169 primary statistic for overall goodness of model fit because it is less sensitive to sample size and

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170 is recommended for confirmatory factor analysis [16]. We reported the chi square statistic ($\chi2$)

171 but did not consider it a determinant of model fit given its sensitivity to large sample sizes, which

172 can overestimate lack of model fit [12].

173   We estimated our sample size using the rule that a minimum of five participants per item

174 are required for factor analysis [17]. With 69 disability severity items in the HDQ, we required at

175 least 345 participants. We used SPSS (version 19.0) for computation of HDQ scores and Mplus

176 (version 7.0) for the confirmatory factor analysis [18, 19].

177 **RESULTS**

178 Three-hundred and sixty-one participants were recruited from AIDS service organizations in

179 Toronto (51%), word of mouth (28%), AIDS service organizations in Hamilton, Niagara and

180 Durham regions (7%), a specialty hospital in Toronto (3%) and hospital clinics in Toronto and

181 other areas of southern, Ontario (3%). The majority of participants were men (80%), the median

182 age was 46 years, most were taking antiretroviral medications (83%), and many (77%) were

183 living with two or more health conditions in addition to HIV (Table 1). The most common self-

184 reported concurrent health conditions included mental health challenges including anxiety and

185 depression (40%), arthritis (27%), osteoporosis or osteopenia (16%) and cardiovascular disease

186 (15%).

187   **Table 1 – Characteristics of Participants (n=361)**

Characteristic	Number (%)
Gender	
Men	289 (80%)
Women	66 (18%)
Transgendered	6 (2%)

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Age (median; 1st-3rd quartile)	46 years (40-52 years)
50 years or older	130 (36%)
Year of diagnosis (median; 1st–3rd quartile)	1998 (1991-2005)
Diagnosed prior to 1996	139 (38%)
Taking antiretroviral therapy	301 (83%)
Nadir CD4 count (<200 cells/mm^3)	167 (46%)
Undetectable Viral Load	196 (76%)
Earning between $10,000-20,000 CAN per year	192 (53%)
Currently working for pay	72 (20%)
Living alone	227 (63%)
Have Children	117 (32%)
Live with children	26/117 (22%)
Self-Rated Health Status	
Poor	22 (6%)
Fair	75 (21%)
Good	138 (38%)
Very Good	82 (23%)
Excellent	42 (12%)
Two or more concurrent health conditions	279 (77%)
Common Concurrent Health Conditions	
Mental Health	143 (40%)
Arthritis	97 (27%)
Osteoporosis or Osteopenia	59 (16%)
Cardiovascular Disease (e.g. heart attack or stroke)	55 (15%)
Hepatitis C	51 (14%)
Cancer	40 (11%)
Diabetes	39 (11%)
Neurocognitive Decline	36 (10%)
Liver Disease	36 (10%)

Not all characteristics will add to the total n due to missing responses.

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188 **HIV Disability Questionnaire**

189 Participants took a median of 14 minutes to complete the HDQ (1st-3rd quartile: 10-20 minutes).

190 Almost all HDQ items (n=66) demonstrated a floor effect with >15% of responses rated '0'

191 indicating no disability. Floor effects were most common in items that referred to symptoms and

192 impairments or difficulties with day-to-day activities. Ten HDQ items demonstrated a ceiling

193 effect with >15% of responses rated '6' indicating the highest severity of disability. Ceiling

194 effects were most common in items pertaining to uncertainty or worrying about the future.

195 Missing responses were <5% across all HDQ disability and episodic items.

196   Median HDQ presence scores (ranging from 0 to 100) ranged from 44 in the difficulties

197 with day-to-day activities domain (1st-3rd quartile: 11-78) to 100 in the cognitive health

198 challenges domain (1st-3rd quartile: 67-100). Median HDQ severity scores were highest in the

199 uncertainty domain (45; 1st-3rd quartile: 27-67) followed by challenges to social inclusion (33;

200 18-51), cognitive (28; 11-50), mental-emotional (27; 14-53) and physical symptoms and

201 impairments (25; 14-38). Median HDQ episodic scores (number of challenges that fluctuated

202 within the week) were greatest in the physical (35; 8-54) and cognitive symptoms and

203 impairments domains (33; 0-67) followed by the mental-emotional symptoms and impairments

204 domain (18; 0-64), difficulties with day-to-day activities (11; 0-33), uncertainty (7; 0-50), and

205 challenges to social inclusion (0; 0-33). The most common health challenges that were reported

206 as episodic spanned the physical and mental-emotional symptoms and impairments and included

207 fatigue (50%), feeling sad, down or depressed (48%), aches and pains (46%), headaches (42%),

208 feeling anxious (41%), having trouble sleeping (40%), and feeling weakness in muscles (40%).

209 Eighty-two percent of participants completed the HDQ on what they considered a 'good day'

210 living with HIV.

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211 **Confirmatory Factor Analysis Results**

212 Results of the confirmatory factor analysis are presented in Table 2. Correlation matrices are

213 available on request. The RMSEA was 0.030 (90% confidence interval: 0.028-0.033), satisfying

214 our primary goodness of fit criterion. The $\chi 2$ value was 3020.981 (p<0.001). Comparative Fit

215 Index (CFI) (0.812) and TLI (0.805) statistics did not meet our pre-specified criteria for

216 goodness of fit. All HDQ items represented our hypothesized domains of disability (factor

217 loadings >0.30). To interpret the first factor loading in Table 2, one standard deviation increase

218 in physical symptoms and impairments is associated with a 0.64 standard deviation increase in

219 loss of energy. Equivalently, the value of the Pearson correlation coefficient between loss of

220 energy and physical symptoms and impairments is 0.64.

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Table 2 - Confirmatory Factor Analysis Results - Domains of Disability in the HIV Disability Questionnaire (HDQ) (n=361)

Domain of Disability (Latent Variables)	Item #	HDQ Items (Indicator Variables)	Standardized Factor Loadings	95% Confidence Interval
Physical Symptoms and Impairments (20 items)	1	I feel too tired to do my usual activities	0.64	0.59-0.70
	2	I have diarrhea	0.34	0.25-0.42
	3	I feel nauseous	0.66	0.60-0.71
	4	I have headaches	0.60	0.54-0.67
	5	I have numbness or tingling in my hands	0.60	0.54-0.67
	6	I have numbness or tingling in my feet	0.58	0.52-0.64
	7	I have aches or pains	0.68	0.64-0.73
	8	I have trouble swallowing food	0.52	0.44-0.59
	9	I have less desire to have sex (decreased libido)	0.46	0.39-0.53
	10	I have shortness of breath	0.59	0.53-0.66
	11	I have fever, chills or sweats	0.57	0.50-0.64
	12	I feel weakness in my muscles	0.73	0.69-0.78
	13	I have muscle cramps	0.67	0.62-0.72
	14	I have stomach cramps	0.63	0.57-0.69
	15	I am losing weight	0.42	0.34-0.50
	16	I lack an appetite for food	0.46	0.39-0.53
	17	I have trouble sleeping	0.50	0.43-0.57
	18	I have problems with my vision	0.57	0.50-0.64
	19	I have problems with my hearing	0.42	0.34-0.50
	20	I feel dizzy	0.70	0.65-0.76
Cognitive Symptoms and Impairments (3 items)	21	I have trouble remembering things like appointments and when to take my medication	0.72	0.67-0.78
	22	I have trouble thinking clearly	0.90	0.87-0.92
	23	I have trouble concentrating	0.87	0.84-0.90

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Mental Health Symptoms and Impairments (11items)	24	I feel anxious	0.67	0.62-0.71
	25	I feel sad, down, or depressed	0.77	0.73-0.80
	26	I am afraid for my future	0.77	0.74-0.81
	27	I lack confidence around others	0.76	0.72-0.81
	28	I am uncomfortable with how my body looks	0.62	0.57-0.67
	29	I feel isolated even when I'm around others. In other words, I feel that I don't belong	0.81	0.78-0.84
	30	I feel embarrassed around others	0.82	0.79-0.85
	31	I feel guilty	0.76	0.72-0.81
	32	I feel lonely	0.75	0.71-0.79
	33	I feel discouraged about my future life options	0.81	0.78-0.84
	34	I feel 'shut out' by my friends or family	0.66	0.60-0.72
Uncertainty or Worry about the Future (14 items)	35	I worry about my future health living with HIV	0.84	0.81-0.87
	36	I worry about my lab test results such as my CD4 count and viral load	0.76	0.72-0.80
	37	I worry about having a serious illness.	0.86	0.84-0.88
	38	I worry about what the outcome of my next episode of illness might be	0.87	0.85-0.89
	39	I worry about the side effects of HIV treatments	0.70	0.66-0.75
	40	I worry about my income or financial security living with HIV	0.68	0.64-0.72
	41	I worry what might happen to my family and friends if I have an episode of illness.	0.68	0.63-0.73
	42	I worry about being able to remain in the workforce or return to the workforce	0.56	0.50-0.62
	43	I worry about dying	0.64	0.58-0.70
	44	I worry about my bodily appearance	0.67	0.62-0.71
	45	I worry about the legal issues of telling others about my HIV status	0.58	0.52-0.63
	46	I worry about what others would think of me if they knew I was HIV positive	0.59	0.54-0.64

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	47	I worry about transmitting HIV to others	0.39	0.31-0.46
	48	I have put certain life decisions on hold (such as buying a house, returning to work or school, or starting a family) because of my uncertainty living with HIV	0.58	0.53-0.64
Difficulties with Day-to-Day Activities (9 items)	49	I am unsteady on my feet	0.69	0.64-0.74
	50	I have trouble walking	0.75	0.70-0.79
	51	I have trouble climbing stairs	0.73	0.69-0.77
	52	I have trouble with daily activities such as eating, bathing, grooming, or dressing	0.71	0.66-0.77
	53	I have trouble doing household chores such as cleaning, doing dishes, laundry, and cooking	0.78	0.74-0.82
	54	I have trouble taking part in leisure or recreation, such as exercise or dancing	0.78	0.74-0.82
	55	I have trouble getting out to do errands such as grocery shopping, banking, or doctor's appointments	0.85	0.82-0.88
	56	I have trouble keeping track of my finances	0.53	0.47-0.60
	57	I have trouble getting around, such as driving or taking public transportation	0.74	0.68-0.79
Challenges to Social Inclusion (12 items)	58	I find it hard to meet the needs of those I care for (such as children, parents, grandparents, partners, or pets)	0.59	0.52-0.66
	59	I find it hard to fulfill my role as a family or community member living with HIV	0.72	0.68-0.76
	60	I feel cut off from my friends, networks, ethnic or religious communities	0.71	0.66-0.76
	61	My illness prevents me from doing volunteer or paid work or going to school	0.60	0.54-0.66
	62	I feel that my work performance is limited because of my illness	0.64	0.59-0.70
	63	I struggle to maintain safe and stable housing living with HIV	0.48	0.41-0.56

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	64	I find it hard to talk with others about my illness, even my family and friends	0.56	0.51-0.62
	65	I find it hard to ask others for help when I go through an episode of illness	0.67	0.62-0.72
	66	I find it hard to start new friendships living with HIV	0.70	0.66-0.75
	67	I find it hard to start new, intimate, sexual relationships living with HIV	0.54	0.48-0.60
	68	I tend to isolate myself from others because I am HIV positive	0.76	0.72-0.80
	69	I find it hard to take part in leisure or recreational things like going to the movies, out to dinner, or on vacation because I can't afford it	0.48	0.41-0.55

Confirmatory Factor Analysis – Goodness of Fit
χ^2 = Chi-square (χ^2)=3020.981 (p value<0.0001)
Degrees of freedom (df) =2262;
Comparative Fit Index (CFI) =0.812 (ideal is $\geq$0.90)
Tucker-Lewis Index (TLI) =0.805 (ideal is$\geq$0.90)
Root Mean Square Error of Approximation (RMSEA) =0.030 (good fit indicated by <0.05)
Results
All standardized factor loadings were statistically significant (p<0.0001);
All factor loadings were >0.30 which indicate the variables 'load' on a given domain of disability.

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233   Factor loadings ranged from 0.34 (item 2: 'I have diarrhea', loading on the physical

234 symptoms and impairments domain) to 0.90 (item 22: 'I have trouble thinking clearly', loading

235 on the cognitive symptoms and impairments domain). Domains of disability correlated with each

236 other ranging from r=0.47 (between difficulties with day-to-day activities and uncertainty) to

237 r=0.88 (between mental-emotional symptoms and impairments and challenges to social

238 inclusion) (Table 3).

239   **Table 3 – Correlations Between Domains in the HIV Disability Questionnaire (HDQ)**
240

HDQ Domain of Disability	HDQ Domain Correlated with…	Factor Loading (Correlation) (Range 0-1)
Cognitive Symptoms and Impairments	Physical	0.70
Mental-Emotional Symptoms and Impairments	Physical	0.64
	Cognition	0.65
Uncertainty	Physical	0.57
	Cognition	0.51
	Mental-Emotional	0.78
Difficulties with Day-to-Day Activities	Physical	0.80
	Cognition	0.59
	Mental-Emotional	0.55
	Uncertainty	0.47
Challenges to Social Inclusion	Physical	0.68
	Cognition	0.64
	Mental-Emotional	0.88
	Uncertainty	0.79
	Day	0.67

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244 **DISCUSSION**

245 This is the first study to assess the construct validity of the HIV Disability Questionnaire, the

246 only HIV-specific measure of disability. Results of our confirmatory factor analysis

247 demonstrated good overall model fit of items with the domain structure, supporting the validity

248 of the six domains of disability in the HDQ.

249   Floor and ceiling effects were evident across the HDQ. We believe that the ceiling effect,

250 primarily seen in items that addressed day-to-day activities, likely reflected the way in which

251 participants were sampled; most were living independently in the community and faced few

252 challenges to mobility or self-care activities. Ceiling effects, with associated severe skewness of

253 item scores, may deflate standard correlation coefficients [20] and lead to an underestimation of

254 factor loadings. While all items loaded significantly on their hypothesized domain of disability

255 (factor loadings > 0.30), the factor loadings might be higher if item response scales were less

256 skewed.

257 Correlations between the latent variables ranged from r=0.47 to r=0.88 (Table 3). A high

258 correlation between mental-emotional challenges and challenges to social inclusion (r =0.88)

259 suggested that these latent variables may not be empirically distinct [12]. However, these

260 domains of disability were represented by items with similar wording, such as 'I feel….'

261 (mental-emotional domain) and 'I find it hard to….' (social inclusion domain) which could

262 explain the high correlation and obscure the discriminant nature between these two domains. The

263 correlation between mental and emotional health challenges and challenges to social inclusion

264 also may reflect the influence of mental health on aspects of social inclusion such as employment

265 among people living with HIV [21, 22]. Overall, we concluded six domains of the HDQ

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266 represent the dimensions that comprise the larger construct of disability. Nevertheless, when

267 administering the HDQ, researchers, clinicians and community members should acknowledge

268 the interrelationships between dimensions of disability and the influence dimensions may have

269 on each other when interpreting HDQ domain scores.

270

271   The prevalence of disability including physical impairments, activity limitations, and

272 social participation restrictions among people living with HIV have been documented using

273 measures based on the International Classification of Functioning, Disability and Health (ICF)

274 [1, 5, 6, 23]. The ICF (and the measures derived from the ICF) do not take into account the

275 domain of uncertainty, nor the episodic nature of HIV. The HDQ was developed from the

276 *Episodic Disability Framework*, a conceptual framework specifically derived and empirically

277 validated from the perspective ofwith, adults living with HIV [7, 8, 24]. Results showed the

278 highest median HDQ severity score was in the uncertainty domain, highlighting the importance

279 of uncertainty as a key component of disability for adults living with HIV. The *Episodic*

280 *Disability Framework* also has been used to inform qualitative approaches to exploring

281 experiences of older men who self-identify as having HIV-associated neurocognitive challenges

282 and considered an approach to conceptualize disability among people living with HIV

283 internationally [25, 26]. However, this is the first known study to use the *Episodic Disability*

284 *Framework* to inform the development and validation of a new quantitative measure of disability

285 for adults living with HIV. With episodic health and disability identified as a key research

286 priority in the HIV and rehabilitation field [27], the HDQ will be integral to accurately and

287 consistently describe the health-related consequences of HIV, aging, and related comorbidities

288 with adults living with HIV.

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289   The highest median HDQ presence score was in the cognitive symptoms and impairments

290   domain. In other studies, self-reported cognitive symptoms have been associated with depression

291   [28]. We confirmed this association in our analysis; the correlation between cognitive and

292   mental-emotional domains was 0.65. While subjectively measured components of mental health

293   correlate with each other, treatment strategies to address mental-emotional and cognitive health

294   symptoms can differ, suggesting these are distinct clinical concepts [29, 30] as represented in the

295   HDQ.

296   Compared with other HDQ domains, symptoms and impairments tended to fluctuate

297   more on a daily basis with median HDQ episodic scores greatest in the physical (35 challenges

298   that fluctuated within the week) cognitive (33 challenges), and mental-emotional (18 challenges)

299   symptoms and impairments domains, demonstrating the potential episodic nature of disability.

300   This was expected given items related to symptoms and impairments such as fatigue, weakness

301   and trouble concentrating may fluctuate more readily than those associated with social inclusion

302   such as the ability to engage or re-engage in the workforce. Specific symptoms and impairments

303   that fluctuated the most included fatigue, feeling sad, down or depressed, aches and pains,

304   headaches, feeling anxious, having trouble sleeping, and feeling weakness in muscles. Despite

305   low episodic domain scores, participants demonstrated a range of episodic health challenges. Our

306   analysis focused on domains of the disability severity scale of the HDQ. Further work is needed

307   to assess the properties of the episodic scale of the HDQ.

308   Lastly, the majority of participants (82%) reported completing the HDQ on a 'good day'

309   living with HIV despite the presence and severity of disability reported in the HDQ. This may be

310   a reflection of resiliency, adaptation and hardiness among people living with HIV [31].

311   Nevertheless, it is unclear how participants in the sample defined a 'good day' versus a 'bad day'

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312 living with HIV. Further work exploring the interpretation of this item as it relates to the HDQ

313 disability scores is needed.

Implications for Practice, Research and Policy

315 The HDQ is the first known HIV-specific disability questionnaire developed to assess the multi-

316 dimensional nature of disability experienced by adults living with HIV. The HDQ has the

317 potential to be used in clinical research, ~~and~~ practice and policy. Patient reported outcome

318 measures are important for their ability to detect disability, monitor disease progression, and

319 facilitate patient-clinician communication [32]. Further psychometric assessment including test-

320 retest reliability, interpretability and responsiveness, will enable researchers to use the HDQ to

321 document the presence, severity and episodic nature of disability experienced by adults living

322 with HIV. The HDQ may be considered for use by clinicians and AIDS service organizations to

323 assess the profile of disability experienced by their clients. This may help to identify areas to

324 implement programs, services and interventions to reduce disability experienced by clients with

325 HIV. Universal measurement of disability with the HDQ may facilitate more broad and ongoing

326 tracking of episodic disability trends and evaluation of interventions to inform resource

327 allocation, as well as income and employment program and policies to ensure optimal care and

328 social inclusion for people living with HIV.

329   Strengths of our analytical approach included our adherence to the COSMIN guidelines

330 for assessing validity and hypothesis testing, such as providing a clear description of the a priori

331 hypothesized measurement model and goodness of fit criteria; providing details on the

332 distribution of HDQ scores and missingness sample; and describing the correlations between

333 domains [33, 34].

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334 　　　Our study has limitations. First, the HDQ was developed and validated primarily with

335 men in their 40s who were taking antiretroviral therapy, living with concurrent health conditions,

336 and not currently working. Generalizability of these findings to the other people living with HIV

337 has not yet been demonstrated. Similarly, the validity of the HDQ in other cultural and

338 developmental contexts is unknown. Second, our goal was to validate the domain structure of the

339 HDQ (not to measure disability) so HDQ scores should be interpreted cautiously. Third, our a

340 priori goodness of fit criteria only was met for the RMSEA. We considered the RMSEA as the

341 primary statistic for overall goodness of model fit because it is recommended for confirmatory

342 factor analysis [16]. Fourth, while our results indicate that dimensions of disability are correlated

343 to comprise the larger construct of disability, the direct relationships between the domains of

344 disability in the HDQ are unknown. Our results provide a measurement model which can serve

345 as the foundation for future structural equation model analyses to determine the relationships

346 between the domains of disability.

347 　　　Our analysis focused on assessing the construct validity of the domains of the disability

348 scale of the HDQ. Future research will assess the test-retest reliability, interpretability, and

349 responsiveness of the HDQ. Additionally, we will consider the measurement properties of the

350 episodic scale. Longitudinally exploring the episodic nature of disability experienced by adults

351 living with HIV is important from the perspective of people living with HIV.

352 **CONCLUSIONS**

353 Results from this confirmatory factor analysis support the validity of the domains of disability in

354 the HDQ when administered to adults living with HIV in Ontario. This is the first known HIV-

355 specific instrument of disability developed from the perspective of adults living with HIV. The

22

356 HDQ can be used to ~~help~~ describe the multi-dimensional nature of disability experienced by

357 adults living with HIV and lay the foundation for _more widespread measurement of disability_ ~~a~~

358 ~~future HIV disability measure used~~ in _HIV_ clinical practice and research.

AUTHORS' CONTRIBUTIONS

360 KKO led the conceptual design of the study, acquisition of funding, conducted the analysis, and

361 drafted the manuscript. AB and PS participated in the conceptual design of the study, acquisition

362 of funding, analytical interpretations and drafting the manuscript. All authors read and approved

363 the final manuscript.

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374 Committee of Durham Region, and AIDS Committee of Toronto.

COMPETING INTERESTS

376 The authors have no competing interests to declare.

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387   **FIGURE LEGENDS**

388   **Figure 1:** *A priori* Measurement Model for Confirmatory Factor Analysis of the HIV Disability

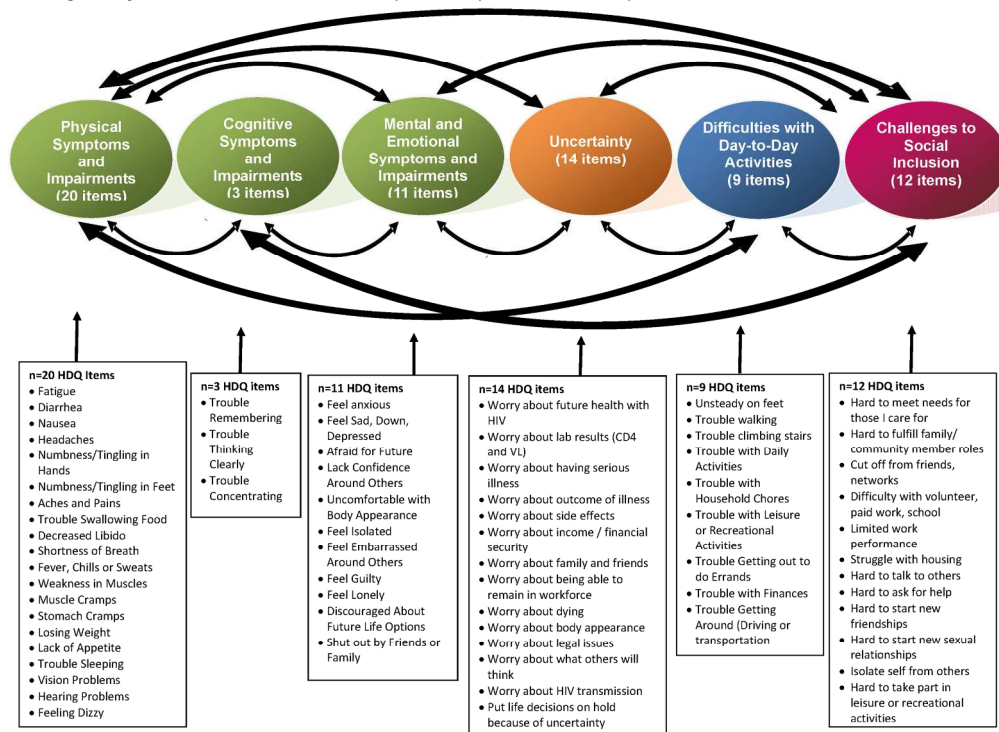389   Questionnaire

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      1219-1221, 1223-1204.

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Figure 1: *A priori* Measurement Model for Confirmatory Factor Analysis of the HIV Disability Questionnaire

215x166mm (300 x 300 DPI)