

Disability Prevalence, Domains and Associations with Age, Among People Living with HIV Accessing Routine Outpatient HIV Care in London, United Kingdom (UK): A Cross-Sectional Self-Report Study

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Background:

HIV is a chronic condition with episodic disability¹. As people living with HIV (PLHIV) live longer they may face new or worsening disability². Disability is defined by PLHIV as any physical, cognitive, mental-emotional symptoms and impairments, difficulties with day-to-day activities, challenges to social inclusion, and uncertainty about future health^{1,3,4}. However the nature and extent of disability experienced by PLHIV in the United Kingdom (UK) is unknown. Our aim was to investigate disability prevalence, and domains, and their associations with age, among PLHIV in London, UK.

Methods:

A quantitative, cross-sectional study was conducted. PLHIV aged ≥ 18 years, stable on HIV treatments for ≥ 6 months, accessing routine outpatient HIV care were recruited. The self-reported WHODAS 12-item questionnaire (6 domains)⁵, HIV Disability Questionnaire (HDQ) (6 domains)⁶, and demographic questionnaire including two disability classification questions from the Equality Act 2010⁷, were administered. Median and interquartile ranges (IQR) for i) WHODAS complex sum (range 0-100), and ii) HDQ domain and total presence, severity and episodic scores (range 0-100) were derived. Prevalence of disability was reported as proportion (95% confidence interval (CI)), defined as achieving severe or moderate thresholds, by i) responding "yes" to both UK Equality Act 2010 items, and ii) scoring ≥ 2 mild/moderate, or ≥ 1 moderate/severe activity limitation on any WHODAS items⁸. Disability domains were reported as i) presence of activity limitations (score ≥ 1) as a percentage per WHODAS domain, and ii) highest median presence, severity, and episodic, domain (subscale) scores. Analysis was explorative and bivariate. Associations between categorised age (< 50 and ≥ 50 years) and all disability variables were examined with Mann-Whitney U and Chi-Squared tests. Critical level of significance adjusted from 0.05 with Bonferonni correction.

Graph One: Frequency of activity limitations (score ≥ 1) across 6 WHODAS disability domains

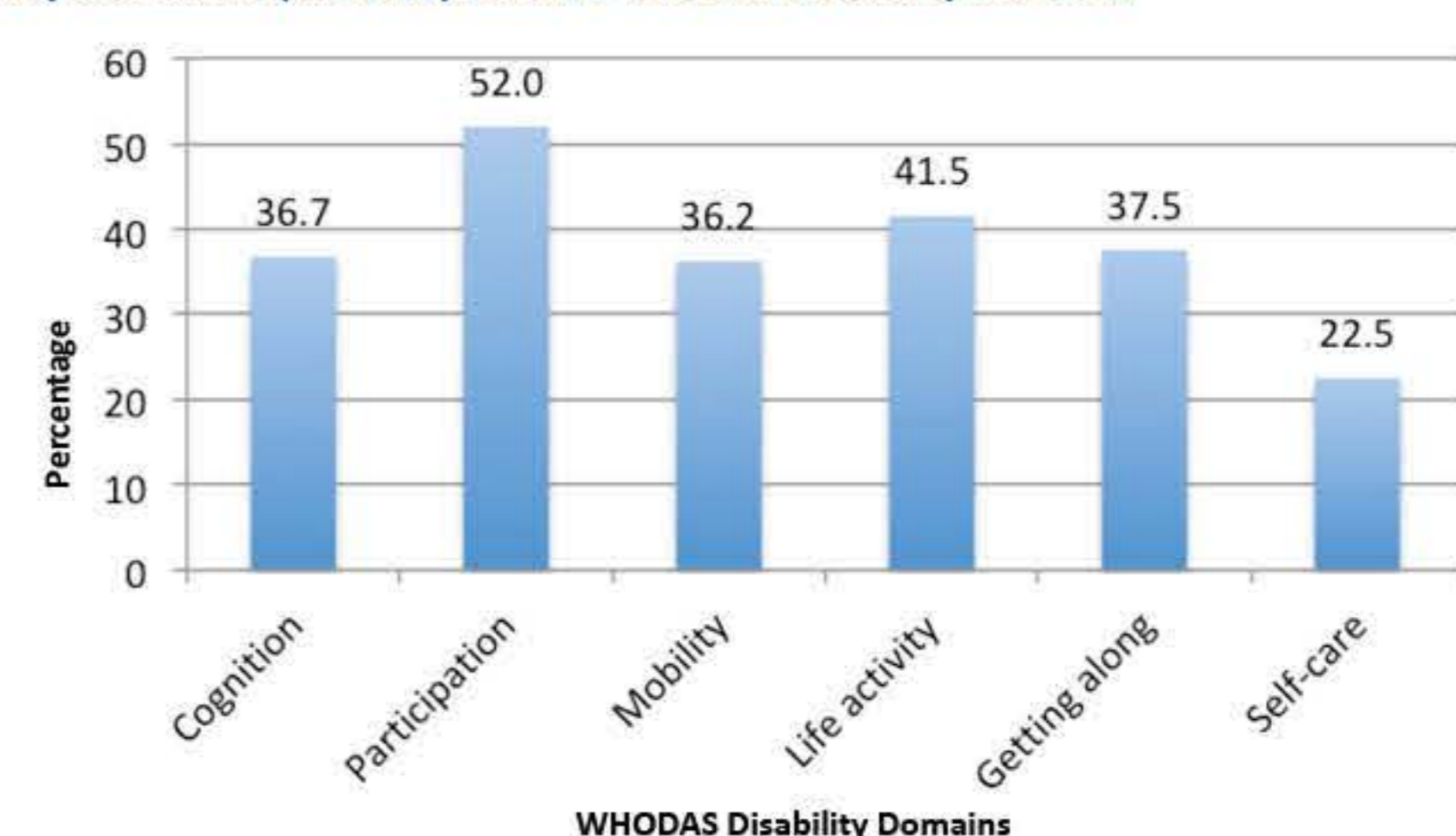


Table One: Median HDQ Dimension Scores

HDQ Disability Dimension	HDQ Presence Score (IQR)	HDQ Severity Score (IQR)	HDQ Episodic Score (IQR)
Physical symptoms and impairments	30.0 (15.0-53.8)	11.3 (5.0-26.3)	20.0 (10.0-40.0)
Cognitive symptoms and impairments	33.3 (0.0-100.0)	8.3 (0.0-25.0)	0.0 (0.0-66.7)
Mental and emotional health symptoms and impairments	45.5 (18.2-72.7)	13.6 (4.5-34.1)	18.2 (0.0-54.5)
Uncertainty or worry about the future	57.1 (28.6-78.6)	23.2 (10.7-38.9)	7.1 (0.0-42.9)
Difficulties with day-to-day activities	11.1 (0.0-44.4)	2.8 (0.0-16.7)	0.0 (0.0-22.2)
Challenges to taking part in social and community life	33.3 (8.3-58.3)	14.6 (4.2-29.2)	0.0 (0.0-25.0)
HDQ Total	36.2 (21.7-59.4)	13.4 (6.3-28.8)	17.4 (5.8-36.2)

IQR: Inter-Quartile Range

Table Two: Median HDQ scores of participants aged < 50 years and ≥ 50 years, and bivariate associations between categorised age and disability dimension scores

Disability Dimension	HDQ Presence Score (IQR)			HDQ Severity Score (IQR)			HDQ Episodic Score (IQR)		
	< 50 years n=118	≥ 50 years n=82	P value	< 50 years n=118	≥ 50 years n=82	P value	< 50 years n=118	≥ 50 years n=82	P value
Physical symptoms and impairments	25.0 (10.0-45.0)	45.0 (20.0-67.5)	$< 0.001^*$	7.5 (3.8-17.5)	18.2 (7.5-39.1)	$< 0.001^*$	20.0 (8.8-40.0)	25.0 (8.8-45.0)	0.385
Cognitive symptoms and impairments	33.3 (0.0-66.7)	66.7 (0.0-100.0)	0.056	8.3 (0.0-25.0)	16.7 (0.0-50.0)	0.015 Δ	33.3 (0.0-66.7)	0.0 (0.0-33.3)	0.065
Mental and emotional health symptoms and impairments	45.5 (18.2-72.7)	50.0 (18.2-81.8)	0.597	13.6 (4.5-29.5)	14.8 (6.2-39.2)	0.355	27.3 (9.1-56.8)	9.1 (0.0-38.7)	0.003 Δ
Uncertainty or worry about the future	57.1 (28.6-78.6)	57.1 (35.7-78.6)	0.929	22.3 (10.3-37.5)	24.2 (12.1-44.2)	0.529	14.3 (0.0-50.0)	0.0 (0.0-23.2)	0.011 Δ
Difficulties with day-to-day activities	11.1 (0.0-22.2)	36.1 (0.0-88.9)	$< 0.001^*$	2.8 (0.0-8.3)	15.3 (0.0-45.8)	$< 0.001^*$	0.0 (0.0-22.2)	0.0 (0.0-33.3)	0.228
Challenges to taking part in social and community life	33.3 (8.3-58.3)	29.2 (8.3-66.7)	0.632	12.5 (4.2-27.1)	15.9 (4.2-15.9)	0.127	0.0 (0.0-25.0)	0.0 (0.0-10.4)	0.181
HDQ Total	32.6 (18.7-52.5)	43.5 (26.1-70.0)	0.007 Δ	12.5 (5.3-24.7)	18.6 (7.8-40.9)	0.010 Δ	18.8 (8.7-36.2)	13.8 (2.9-36.7)	0.173

The adjusted critical level of significance is 0.002. All bivariate associations were performed using Mann Whitney U test.
 *Represents rejection of the null hypothesis. Δ Represents close to significance.
 IQR: Inter-Quartile Range

Results:

Of the 201 participants, 88% were male, mean age of 47 years, 97% were virally suppressed, and living with a median of 2 comorbidities. Median (IQR) WHODAS complex sum (10.4 (IQR 2.1-25.6)), HDQ total presence (36.2 (21.7-59.4)), severity (13.4 (6.3-28.8)) and episodic (17.4 (5.8-36.2)) scores. Prevalence of disability ranged from 40% (79/201) [CI 0.33,0.46] to 71% (141/200) [CI 0.64,0.77] defined by UK Equality Act 2010 and WHODAS presence of activity limitations respectively. Domains of disability experienced included participation (52%), life activities (42%), getting along (38%), cognition (37%), mobility (36%), and self-care (23%), as measured by WHODAS (graph one). Highest presence, severity and episodic subscale scores were in the uncertainty (57/100), uncertainty (23/100), and physical symptoms and impairments (20/100) domains, respectively (table one). Compared to younger participants (< 50 years), older participants (≥ 50 years) reported greater presence ($P < 0.001$) and severity ($P < 0.001$) of physical symptoms and impairments, and greater presence ($P < 0.001$) and severity ($P < 0.001$) of difficulty performing day-to-day activities, as measured by HDQ (table two).

Conclusion:

Prevalence of self-reported disability ranged from 40-71% in a sample of PLHIV accessing routine outpatient HIV care in London, UK. Disability experienced by PLHIV is multi-dimensional and episodic in nature, spanning all WHODAS domains, and experienced most in HDQ uncertainty and physical domains. Exploratory analysis demonstrated that participant's ≥ 50 years reported different disability domains compared to younger participants. Results can help providers better understand the nature and extent of disability experienced by PLHIV in the UK. Next steps include multivariate analysis to explore further associations with disability.

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