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 health13. 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 WHOQOL 10-item questionnaire (6 domains), HIV Disability Questionnaire (HDQ) (6 domains), and demographic questionnaire including two disability classification questions from the Equality Act 2010 were administered. Median and interquartile ranges (IQR) for WHOQOL complex sum (range 0-100) and 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 ≥1 mild/moderate, or ≥1 moderate/severe activity limitation on any WHOQOL items3. Disability domains were reported as i) presence of activity limitations (score ≥1) as a percentage per WHOQOL 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 Bonferroni correction.

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) WHOQOL 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 WHOQOL 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 WHOQOL (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 WHOQOL 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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