

ORIGINAL ARTICLE

Disability and frailty in people living with Human Immunodeficiency Virus in regional Australia: A cross-sectional study with a measurement property assessment of the HIV Disability Questionnaire

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Abstract

Objectives: To measure disability and frailty and assess measurement properties of the HIV Disability Questionnaire (HDQ) in outer regional Australian people living with human immunodeficiency virus (HIV).

Methods: This cross-sectional, validity and reliability study included community-dwelling outer regional Australian adults with HIV. Participants completed the self-reported World Health Organization Disability Assessment Schedule 2.0 (WHODAS; scored 0–100), 5-Question Frail Scale (scored 0–5) and HDQ (scored 0–100). Median scores (Q1, Q3) for disability (WHODAS) and frailty (Frail Scale) were reported. HDQ validity was tested based on 16 a priori hypothesized relationships between WHODAS, Frail Scale and HDQ scores (threshold $\geq 75\%$ confirmed), and HDQ internal consistency with Cronbach's alpha (acceptability threshold ≥ 0.70). Seven days after the initial completion, the HDQ was re-administered for test–retest reliability (intraclass correlation coefficient, acceptability threshold ≥ 0.75).

Results: Fifty participants were recruited, with a median age 55. Eighty-eight percent were male, and 38 participants completed the second HDQ. The median (Q1, Q3) scores were: WHODAS 9 (3,17), with domain scores ranging from 0 to 56. Pre-frailty (score 1–2) and Frailty (score 3–5) were present in 27% and 13% of participants, respectively. The HDQ demonstrated construct validity (81% hypotheses confirmed), internal consistency (Cronbach's alpha ≥ 0.79), except in the Episodic scale-Social inclusion domain (alpha = 0.34), and good test–retest reliability for all Presence and Severity domains (ICC range: 0.77–0.94).

Conclusions: Disability, frailty and pre-frailty exist in this sample of outer regional Australians living with HIV. The HDQ showed acceptable construct validity, internal consistency and test–retest reliability to measure disability in

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this population. Clinical trial registration: Australian New Zealand Clinical Trials Registry (ACTRN12623000090617).

KEYWORDS

Australia, disability, frailty, HIV, reliability, validity

INTRODUCTION

The mortality rate amongst people with human immunodeficiency virus (HIV) is declining in resource-rich nations, resulting in increased life expectancy [1], due in part to greater access and adherence to antiretroviral therapy (ART) [2]. Although a manageable chronic disease [1], people with HIV remain disproportionately affected by physical and psychological health challenges when compared with people not living with HIV [3]. These challenges relate to ageing with HIV [4], direct effects of HIV infection or sequelae of ART [5], predisposing people to reduced physical, psychological and social function. Moreover, people living with HIV demonstrate significant epigenetic age acceleration (median 1.9–4.8 years) with earlier onset of clinical aging [6], compared to people not living with HIV, potentiating disability and frailty [4, 7].

Episodic disability is a feature of HIV similarly observed in multiple sclerosis and rheumatoid arthritis [8] which is due to unpredictable illness and wellness occurrences [9]. Disability may be accentuated by frailty [10], a syndrome presenting clinically with lowered physiological capacity and greater vulnerability to stressors, which reduces a person's ability to compensate for loss of function and predisposes to poor health outcomes [11]. Frailty has been identified in people with HIV at a younger age compared to people without HIV [12]. This combination of disability and frailty is important because both are known determinants of reduced quality of life [13].

A 40% prevalence of moderate-to-severe physical function limitations has been reported in Australian gay and bisexual men with HIV [14]. However, the study did not include females or outer regional Australians with HIV, who have unique cultural profiles and poorer health care access [15, 16]. Thus, research on disability and frailty specific to regional Australian people with HIV is needed.

The HIV Disability Questionnaire (HDQ) is an HIV-specific self-reported outcome measure that describes the presence, severity and episodic nature of disability amongst people with HIV. It is the first known measure of episodic disability and has demonstrated construct validity, internal consistency (Cronbach's $\alpha > 0.85$; Kuder–Richardson-20 > 0.80) and test–retest reliability

(intraclass correlation coefficient [ICC] ≥ 0.75) in adults with HIV in Canada, Ireland, the United States and the UK [17–19]. The suitability of the HDQ for people with HIV in regional Australia is yet to be established.

The first aim of this study was to examine disability using the World Health Organization Disability Assessment Schedule 2.0 (WHODAS) and report scores from the 5-Question Frail Scale (Frail Scale) screening tool in adults with HIV in regional Australia. The second aim was to assess the measurement properties of the HDQ (construct validity, internal consistency and test–retest reliability).

MATERIALS AND METHODS

Study design and setting

This two-part study was registered with the Australian New Zealand Clinical Trials Registry (ACTRN: 12623000090617) and conducted between April 2021 and April 2024 at an Australian outer regional sexual health service. Part 1 was a single centre cross-sectional study of self-reported measures of disability and frailty. Part 2 was a study of the measurement properties of the HDQ. The CONsensus-based Standards for the selection of health Measurement INSTRuments criteria guided Part 2 [20]. The human research ethics committees of Townsville Hospital and Health Services (HREC/QTHS/66818) and James Cook University (H8322) approved this research.

Participants and investigators

Participants were recruited via purposive sampling while attending a sexual health service for outpatient HIV care in outer regional Australia. Investigators were health researchers and a site-based nurse with 38 years of HIV and sexual health experience.

Eligible participants were community-dwelling adults with HIV (18 years or older) from regional, rural or remote areas in Northern Australia and who were able to understand and complete all study requirements. To ensure eligibility, volunteers were required to demonstrate the ability to provide written informed consent and

complete self-administered questionnaires in English. Therefore, during the initial study communication, the site-based nurse applied experiential communication skills to assess volunteers' language ability and comprehension (reading, listening and speaking English).

Outcome measures

For the first aim, the WHODAS and Frail Scale were used to measure disability and frailty, respectively. The WHODAS 36-item generic disability self-reported questionnaire assesses health and disability across six domains linked to the International Classification of Functioning, Disability and Health [21]. Items are scored 'none', 'mild', 'moderate', 'severe' and 'extreme', and the six domains are scored from zero (indicating no disability) to 100 (full disability) [21]. The presence of disability was defined as a WHODAS score ≥ 2 [22]. The WHODAS has been reported in the context of HIV previously [22–26], with acceptable to good internal consistency for Brazilian people with HIV (Cronbach's alpha range 0.69 to 0.87) for all domains except self-care (alpha = 0.32) [27].

The Frail Scale self-reported questionnaire is a five-item scale, with zero representing 'Robust' health, one to two 'Pre-frail' and three to five 'Frail' [28]. The Frail Scale is one of several recommended tools to screen for frailty in people with HIV [29]. In older Australian females without HIV, the Frail Scale has demonstrated good construct validity against the Katz index of independence for activities of daily living ($r_s = 0.48$, 95% CI 0.45, 0.51), and Lawton's instrumental activities of daily living scale ($r_s = 0.52$, 95% CI 0.49, 0.55) [30].

For the second aim, the HDQ was administered followed by re-administration of the HDQ 1 week later. The HDQ is a 69-item patient-reported outcome measure that describes the presence, severity and episodic nature of HIV-related disability across six domains: (i) physical health impairments; (ii) cognitive health impairments; (iii) mental-emotional health impairments; (iv) difficulties with day-to-day activities; (v) uncertainty and worry about the future; and (vi) challenges to social inclusion [9, 31]. Item scores range from zero (none) to four (severe) for the Presence and Severity scales. For the Episodic scale, respondents report for each item either yes or no if their health-related challenges have fluctuated in the past week, and whether they completed the questionnaire on a 'Good day' or 'Bad day'. HDQ scale and domain scores range from 0 to 100. Higher scores indicate greater disability [32].

Personal and HIV health characteristics

A self-administered questionnaire was used to capture participants' age, sex at birth, body mass index, years since HIV diagnosis (polymerase chain reaction and Western Blot test), years taking their current ART, ethnicity defined by the Australian Standard Classification of Cultural and Ethnic Groups [33], employment status, residence type, number of people in household and non-HIV related health conditions or disabilities prior to HIV diagnosis. Latest CD4+ cell count (cells/ μ L) and viral suppression (viral load ≤ 200 copies/mL) were extracted from electronic health records.

Study procedure

Recruitment was done through sexual health-related notice boards, newsletters and community-based HIV advocacy social media groups. Potential participants gained information about the study from the research coordinator at the clinical site either through phone contact or in person on attendance for HIV care. Part 1 study procedures were embedded within participants' HIV care appointment at the clinical site. All participants were screened for eligibility and provided written consent prior to commencement. Figure 1 details participants' flow through the study once consent was obtained. Participants completed the WHODAS, Frail Scale, initial HDQ (HDQ1) and demographic information using paper-based questionnaires at the clinical site. A second HDQ (HDQ2) along with a cover sheet and postage paid envelope were provided to be completed at home 7 days later. The cover sheet asked participants to report any changes

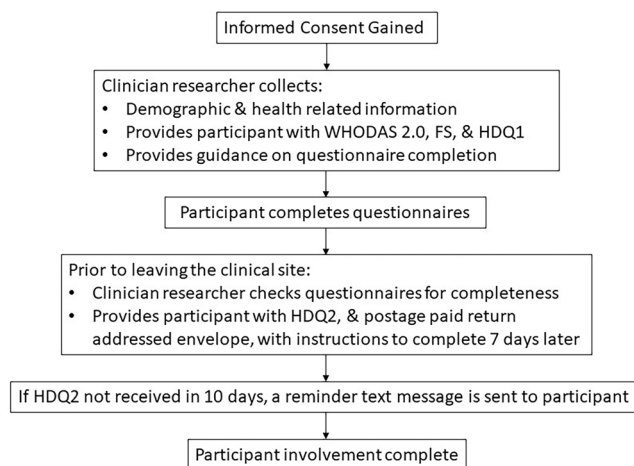


FIGURE 1 Study procedure flow chart. FS, 5-Question Frail Scale; HDQ, HIV Disability Questionnaire; WHODAS-2.0, World Health Organization Disability Assessment Schedule.

in their health status between completion of HDQ1 and HDQ2.

Data analysis

Analysis was conducted using *R* version 4.4.2. Personal and HIV health characteristics were reported as frequencies, proportions (%) or median (Q1, Q3). Questionnaires were scored according to the relevant instruction manuals [21, 28, 32]. WHODAS scores were calculated using the complex item response theory (IRT) scoring guidance [21]. The Frail Scale was reported as a 0–5 score. Cases with missing HDQ 1 and 2 responses were only included for analysis where over 50% of items in a domain were available.

The median and interquartile range (Q1, Q3) were calculated for each of the six HDQ domains across the Presence, Severity and Episodic scales. For the Presence scale, the number of items (out of 69) that scored ≥ 1 was added, and this sum was transformed to a range of 0 to 100 for each domain. For the Severity scale, all items were added, and this sum was then transformed to a range of 0 to 100 for each domain. For the Episodic scale, the number of items where a respondent indicated 'yes' to a fluctuation in their health-related challenge was added, then this sum was transformed to a range of 0 to 100.

Construct validity of the HDQ was assessed using Pearson's correlation coefficients, testing 16 a-priori hypotheses assessing theorized relationships between the HDQ and WHODAS and Frail Scale scores as criterion measures using similar approaches to O'Brien et al. [17]. Correlation coefficients of ≥ 0.30 , ≥ 0.50 and ≥ 0.70 were considered weak, moderate and strong respectively [34]. Construct validity of the HDQ was indicated if $\geq 75\%$ of hypotheses were confirmed [35].

Internal consistency was reported using Cronbach's alpha, and test-retest reliability using intraclass correlation coefficients (ICC) for HDQ domain scores of the Presence, Severity and Episodic scales. The acceptability thresholds were alpha ≥ 0.70 [35], and ICC ≥ 0.75 . The ICC 95% confidence interval was used to guide the interpretation of test-retest reliability, where ICC < 0.5 , 0.5–0.74, 0.75–0.89 and > 0.90 are often used to indicate poor, moderate, good and excellent reliability, respectively [36]. In assessing test-retest reliability for the Presence and Severity scales, the anticipated result was for high levels of agreement between the scores, whereas for the Episodic scale, it was anticipated that there would be low agreement in scores due to the unpredictability of disabilities experienced by people living with HIV.

A target sample size of 54 participants was estimated to assess test-retest of a single measurement instrument

or comparing two measurement instruments with reference to Cronbach's alpha of approximately 0.90 with a 95% CI width of around 0.10 from previous studies [27, 31, 37]. This was considered feasible to achieve given the estimated population of community-dwelling people with HIV in outer regional Australia.

RESULTS

Fifty participants were recruited from April 2021 to March 2024. All participants completed the HDQ1, 49 completed the WHODAS and 45 completed the Frail Scale. The HDQ2 was returned by 38 participants (76%). HDQ1 to HDQ2 completion time ranged 5 to 9 days. Table 1 shows a summary of participants' personal and HIV health characteristics. Most participants identified as male (88%), with a median of 13 years since their HIV diagnosis. Most participants (92%) were virally suppressed (viral load was < 200 copies/mL).

HIV disability and frailty

Table 2 shows WHODAS and Frail Scale scores. Disability was not present in six participants (WHODAS score < 2), three of which scored zero. The median overall WHODAS disability score was 9 (3, 17) and ranged from 0 to 56. The median domain disability was lowest for Self-care, 0 (0, 6) and highest in the Getting along domain, 10 (4, 25). The median Frail scale score was 0 (0, 1). Thirteen percent of participants were classified as Frail ($N = 6$; age 56–68 years), 27% were Pre-frail ($N = 12$; age 25–66 years) and 60% were classified as Robust, with no indication of frailty ($N = 27$; age 25–77 years). Amongst participants 50 years and older 19% were Frail ($N = 6$), 19% were Pre-frail ($N = 6$) and 63% were Robust ($N = 20$). No participants under 50 years of age were Frail, 46% were Pre-frail ($N = 6$) and 54% were Robust ($N = 7$).

HDQ measurement properties

HDQ1 and 2 scores presented in Table 3 provide information and context for the HDQ measurement properties assessment. HDQ construct validity is presented in Table 4. Thirteen of the 16 hypotheses tested for Pearson's correlation were confirmed (81%) as meeting the criteria for construct validity.

For the HDQ Severity scale, Cronbach's alpha ranged from 0.87 (cognitive) to 0.95 (mental-emotional) across the six domains indicating internal consistency (Table 5).

TABLE 1 Personal and HIV health characteristics.

Characteristic	N	Summary median (Q1, Q3)
Age (years)	50	55 (46, 62)
Sex	49	
Male		43 (88%)
Female		6 (12%)
Body mass index	50	26 (23, 32)
Years since HIV diagnosis	50	13 (7, 20)
Duration of current ART (years)	50	2 (1, 3)
CD4+ count (cells/ μ L), latest	48	810 (555, 1070)
CD4+ count $\geq$ 500		37 (79%)
Viral suppression (viral load $\leq$ 200 copies/mL), latest		44 (92%)
Ethnicity	48	
Australian		36 (75%)
European		7 (15%)
Other ^a		5 (10%)
Employment status	50	
Full-time paid		20 (40%)
Retired		13 (28%)
Part-time paid		7 (14%)
Unemployed		7 (14%)
Undisclosed		3 (6%)
Type of residence	49	
House		33 (67%)
Unit/apartment		13 (27%)
Undisclosed		3 (6%)
People in household	48	
Spouse/partner		23 (48%)
Alone		14 (29%)
Undisclosed		11 (23%)
Health conditions or registered disabilities prior to HIV diagnosis		14 (28%)

Abbreviation: ART, antiretroviral therapy.

^aIncludes Asia-Pacific (excl Australia) and the Americas.

For the Presence scale, Cronbach's alpha ranged from 0.79 (cognitive) to 0.88 (day-to-day activities and social inclusion). For the Episodic scale, Cronbach's alpha ranged from 0.34 (social inclusion) to 0.93 (day-to-day activities).

Table 6 shows the HDQ test-retest reliability results. One participant reported a health status change between HDQ1 and HDQ2 completion, these scores are reported in Table 3 but were excluded from the test-retest reliability analysis. The HDQ met the criteria for test-retest

TABLE 2 Frail scale and World Health Organization Disability Assessment Schedule (WHODAS) scores.

	N	Score median (Q1, Q3)
Frail scale ^a		Min 0 to Max 3
Total score	45	0 (0, 1)
Robust		27 (60%)
Pre-frail		12 (27%)
Frail		6 (13%)
WHODAS domain scores		Min 0 to Max 56
Cognition	49	8 (0, 21)
Mobility	49	5 (0, 20)
Self-care	49	0 (0, 6)
Getting along	48	10 (4, 25)
Life activities	48	6 (0, 17)
Participation	48	9 (3, 23)
Total score	49	9 (3, 17)

^aFrail scale score, 0–5; WHODAS scores, 0–100.

reliability for all domains in the Presence and Severity scales. For the Presence and Severity scale total score, test-retest reliability was good to excellent at 0.94 (0.86, 0.97) and 0.94 (0.84, 0.98), respectively. The highest domain-based agreement was excellent for Severity-Mental-Emotional at 0.95 (0.91, 0.98), and lowest agreement was moderate to good for Presence-Physical at 0.77 (0.46, 0.89).

DISCUSSION

This was the first study to report disability and frailty and assess the measurement properties of the HDQ in community-dwelling people with HIV in outer regional Australia. Results indicate that both disability and frailty are independently prevalent, with only six participants scoring below the WHODAS disability threshold (≥ 2), and 40% of participants reporting as frail or pre-frail. Our study did not aim to explore any relationship between frailty and disability. However, such a relationship has been suggested previously in older community dwelling individuals [38], suggesting frailty as a predictor of future disability. Findings from our study have clinical and service implications because this group of people living with HIV would not only be exposed to the poor healthcare access and outcomes common amongst regional and rural Australians [39], but may also face additional challenges related to stigma, fear of HIV status exposure and absence of HIV specific medical services [40].

TABLE 3 HIV Disability Questionnaire (HDQ) scores.

HDQ scales and domains	HDQ time point 1		HDQ time point 2	
	N	Score median (Q1, Q3)	N	Score median (Q1, Q3)
Presence scale				
Physical	50	40 (20, 60)	38	30 (11, 40)
Cognitive	50	67 (0, 100)	38	33 (0, 67)
Mental-emotional	50	45 (18, 73)	38	41 (18, 66)
Uncertainty	50	54 (29, 79)	37	43 (14, 79)
Day-to-day activities	50	11 (0, 36)	38	0 (0, 22)
Social inclusion	49	25 (11, 58)	37	25 (8, 58)
Total score	50	41 (25, 56)	38	31 (18, 49)
Severity scale				
Physical	50	13 (7, 23)	38	10 (3, 14)
Cognitive	50	17 (0, 25)	38	8 (0, 17)
Mental-emotional	50	14 (5, 25)	38	10 (5, 23)
Uncertainty	50	20 (10, 35)	37	16 (4, 34)
Day-to-day activities	50	4 (0, 11)	38	0 (0, 8)
Social inclusion	49	11 (6, 23)	37	13 (2, 21)
Total score	50	14 (8, 21)	38	10 (5, 18)
Episodic scale				
Physical	42	8 (0, 21)	35	5 (0, 13)
Cognitive	42	0 (0, 0)	35	0 (0, 0)
Mental-emotional	42	0 (0, 20)	36	0 (0, 11)
Uncertainty	42	0 (0, 0)	35	0 (0, 7)
Day-to-day activities	42	0 (0, 0)	36	0 (0, 0)
Social inclusion	41	0 (0, 0)	34	0 (0, 0)
Total score	42	3 (0, 16)	36	1 (0, 7)

Note: HDQ scores range from 0 to 100; higher scores indicate greater presence, severity and episodic nature of disability.

Personal and HIV health characteristics

Participants' median age of 55 years was slightly older than in previous reports of disability in people with HIV using the WHODAS from Cote D'Ivoire [23], South Africa [22], Nigeria [26], the United Kingdom [24], the United States and South Africa [25] at 50, 42, 44.2, 47 and 49.6 and 41.8 years respectively. Males represented 88% of participants, comparable with the UK study by Brown et al. [24] but not with other studies which have included females predominantly [22, 23, 25, 26]. The median of 13 years since HIV diagnosis reflects several previous studies (range 7–15 years) [17, 18, 24–26]. Further, all participants were on ART, aligning with UK (97%), South African (100%) and Nigerian (100%) studies [22, 24, 26], but marginally higher than Canadian (91%), Irish (88%) [17] and US (96%) studies [18]. Brown et al. [24] reported that 97% of UK

participants were virally suppressed, which is comparable to the 92% of this sample.

The 54% of participants with some type of paid employment is consistent with previous reports for people with HIV in Ireland (54%), South Africa (58%) and the Cote D'Ivoire (51%) [17, 22, 23]. However, proportions reported were demonstrably lower in other studies from Canada, the United States and South Africa and the United Kingdom, at 21%, 25% and 39% and 46%, respectively [17, 24, 25]. In summary, several similarities in participant characteristics are apparent between this Australian study and previous research findings which facilitate between study comparability. Similarities include but are not limited to the study by Brown et al. [24] for years from HIV diagnosis, proportions of males and females and people on ART and virally suppressed.

TABLE 4 Pearson *r* correlations for HIV Disability Questionnaire (HDQ) components versus the Frail scale and WHODAS-2.0, World Health Organization Disability Assessment Schedule (WHODAS).

Scale	HDQ	Pearson's <i>r</i> (95% CI)	A prior Pearson's <i>r</i>	Confirmed?
Frail scale	Presence scale			
Total score	Physical domain	0.43 (0.15, 0.65)	≥0.70	No
	Day-to-day activities domain	0.72 (0.54, 0.84)	≥0.70	Yes
WHODAS domains	Severity scale			
1 Cognition	Cognitive domain	0.72 (0.56, 0.84)	≥0.70	Yes
1 Cognition	Mental-emotional domain	0.53 (0.29, 0.70)	≥0.50	Yes
2 Mobility	Day-to-day Activities domain	0.77 (0.63, 0.87)	≥0.70	Yes
3 Self-care	Day-to-day Activities domain	0.56 (0.33, 0.73)	≥0.70	No
4 Getting along	Social Inclusion domain	0.69 (0.50, 0.81)	≥0.50	Yes
5 Life activities	Day-to-day Activities domain	0.68 (0.49, 0.81)	≥0.70	No
6 Participation	Social Inclusion domain	0.82 (0.70, 0.90)	≥0.70	Yes
WHODAS	Severity scale			
Total score	Physical domain	0.77 (0.62, 0.86)	≥0.70	Yes
	Cognitive domain	0.72 (0.55, 0.83)	≥0.70	Yes
	Mental-emotional domain	0.75 (0.59, 0.85)	≥0.70	Yes
	Uncertainty domain	0.57 (0.34, 0.73)	≥0.50	Yes
	Day-to-day Activities domain	0.72 (0.54, 0.83)	≥0.70	Yes
	Social Inclusion domain	0.80 (0.66, 0.88)	≥0.70	Yes
	Total score	0.84 (0.73, 0.91)	≥0.70	Yes
Total number of hypotheses confirmed				13/16 (81%)

Abbreviation: CI, confidence interval.

TABLE 5 Cronbach's alpha (95% confidence interval [CI]) for HIV Disability Questionnaire (HDQ) presence, severity and episodic scales.

HDQ domain	Severity	Presence	Episodic
Physical	0.90 (0.85, 0.93)	0.87 (0.81, 0.92)	0.90 (0.85, 0.93)
Cognitive	0.87 (0.79, 0.92)	0.79 (0.67, 0.87)	0.85 (0.76, 0.91)
Mental-emotional	0.95 (0.92, 0.97)	0.86 (0.80, 0.91)	0.87 (0.81, 0.92)
Uncertainty	0.92 (0.88, 0.95)	0.86 (0.79, 0.91)	0.85 (0.78, 0.90)
Day-to-day activities	0.92 (0.89, 0.95)	0.88 (0.83, 0.93)	0.93 (0.90, 0.96)
Social inclusion	0.90 (0.86, 0.94)	0.88 (0.83, 0.93)	0.34 (0.02, 0.59)

Disability

The median total WHODAS score in this study was 9, which is lower than reported in some previous studies on this topic [23–26]. In relation to individual WHODAS domains, participants experienced the most difficulties with getting along, participation and cognition. There were fewer difficulties with life activities, mobility and self-care. Similar patterns exist in recent studies from Nigeria and the United Kingdom, with higher disability scores for participation in society of 32 and 52, and lower

scores for self-care at 11 and 13, respectively [24, 26]. Moreover, people with HIV in the Cote D'Ivoire study reported that getting along more challenging than a comparison population of people not living with HIV [23]. This suggests that the challenges faced by people with HIV in this regional Australian population mimic those reported in at least one European and two African countries. Including psychosocial elements such as social inclusion activities concurrent with physical components in rehabilitation for people living with HIV is indicated. Although the median total WHODAS score was lower

TABLE 6 ICC(A,1)^a for HIV Disability Questionnaire test–retest reliability.

Description	ICC (95% CI)
Presence scale (<i>N</i> = 37)	
Physical domain	0.77 (0.46, 0.89)
Cognitive domain	0.85 (0.73, 0.92)
Mental–emotional domain	0.90 (0.82, 0.95)
Uncertainty domain	0.84 (0.72, 0.92)
Day-to-day activities domain	0.88 (0.77, 0.94)
Social inclusion domain	0.91 (0.84, 0.96)
Total score	0.94 (0.86, 0.97)
Severity scale (<i>N</i> = 37)	
Physical domain	0.83 (0.55, 0.92)
Cognitive domain	0.83 (0.69, 0.91)
Mental–emotional domain	0.95 (0.91, 0.98)
Uncertainty domain	0.87 (0.77, 0.93)
Day-to-day activities domain	0.92 (0.85, 0.96)
Social inclusion domain	0.88 (0.76, 0.94)
Total score	0.94 (0.84, 0.98)
Episodic scale (<i>N</i> = 31)	
Physical domain	0.53 (0.23, 0.74)
Cognitive domain	0.44 (0.12, 0.68)
Mental–emotional domain	0.24 (0.00, 0.55)
Uncertainty domain	0.02 (0.00, 0.37)
Day-to-day activities domain	0.50 (0.19, 0.72)
Social inclusion domain	0.17 (0.00, 0.49)
Total score	0.41 (0.08, 0.66)

Abbreviations: CI, confidence interval; ICC, intraclass correlation coefficient.

^aICC(A,1) is a two-way mixed, absolute agreement, single measure.

than reported for South Africa and the United States [25], Nigeria [26], the United Kingdom [24] and Cote D'Ivoire [23], it is notable that some of these studies used the 12 item WHODAS, rather than the 36-item used here and not all studies used the IRT scoring method meaning that scores may not be directly comparable.

Frailty

This study demonstrated concerning levels of frailty and pre-frailty. Particularly, pre-frailty amongst those 50 years or younger (46%), which was not unexpected because people living with HIV aged 50 years or more are considered 'older' [41], compared with adults 65 years or more without HIV [42]. People with HIV are predisposed to age-related illness earlier compared to

people not living with HIV [43], and Paolillo et al. [44] indicated pre-frailty may be a risk factor for cognitive decline in people with HIV and that targeted interventions are needed. Others have suggested that supervised physical activity and resistance training interventions increase functional capacity, and psychosocial approaches to increase social and emotional support may prevent frailty in people living with HIV [45, 46]. Thus, it is recommended that rehabilitation should be supervised and include both physical and psychosocial components to address frailty and pre-frailty in people with HIV. This should be a focus for future research, particularly as reducing frailty progression is an Australian Health objective [47].

HDQ measurement properties

The HDQ demonstrated construct validity for use in this population. The number of confirmed hypotheses was comparable to previous Canadian, Irish, and US studies [17, 18]. The moderate correlation between the Frail Scale score and the HDQ Presence scale-Physical may be because the HDQ measures the construct of disability, not frailty, and the Frail Scale explores 11 specific medical conditions, which the HDQ does not. Internal consistency of the Episodic scale was good, albeit for Episodic-Social inclusion. The HDQ demonstrated good to excellent test–retest reliability for the Presence and Severity scales. The Episodic scale did not show acceptable test–retest reliability because that scale measures fluctuations over time; hence, consistency was not expected in this scale. Conversely, presence and severity measure reasonably stable constructs over the same period. The HDQ is an appropriate outcome measure of disability for people with HIV in outer regional Australia. However, in the long-form version, the episodic disability reported should be considered judiciously and in consideration of study limitations associated with low response to the HDQ Episodic scale items, generalizability, sample size and sex-based recruitment ratio.

Almost a third of participants failed to answer the HDQ Episodic scale items, and although this study did not explore reasons for this, others report the long form HDQ to be comprehensive but lengthy [48], which may explain participants' disinclination to respond. Since the inception of this study, the Short-Form HDQ [49, 50] and the Episodic Disability Questionnaire [51] have evolved as measures of disability for people with HIV and other conditions that demonstrate episodic disability.

Findings herein are limited to community-dwelling people with HIV and one sexual health service in outer regional Australia and cannot be generalized to

non-community-dwelling people with HIV in metropolitan areas or people with HIV who access care from a general practitioner or other care providers. Neither the Nadir CD4 count nor the CD4/CD8 ratio was reported in this study. As such, the historical harm of HIV indicated by Nadir CD count and the degree of immune dysfunction indicated by CD4/CD8 ratio on participants' current health should not be assumed from the results herein. This study did not attempt to explore differences between level of reported disability and frailty profiles, as the sample size was insufficient to conduct such an analysis. As such, no causal inferences between frailty and disability should be deduced. However, such exploration would be worthy of future research.

One-third of patients registered at the study site volunteered for this research, but participant numbers were smaller than in related studies [22–26], conducted in countries with higher HIV prevalences than Australia (0.1%; low to high uncertainty bounds <0.1–0.1) such as the Cote D'Ivoire 1.7% (1.5–1.9), South Africa 17.2% (14.5–19.5), Nigeria 1.2% (1.1–1.2), the UK 0.2% (0.2–0.2) and the United States 0.4% [52, 53]. Further, several female migrants volunteered for this study but were excluded because they lacked the English language skills to complete the self-administered versions of the questionnaires, partly explaining the predominance of male participants. Given Australia's lower overall HIV prevalence and this study's less populous regional setting these limitations to sample size and sex-based recruitment ratios might be expected.

Future research

A larger multi-centre study is needed to report disability and frailty in people with HIV in other regional areas of Australia and in rural and remote communities. This would provide further knowledge of the extent of disability and frailty amongst those who live outside of metropolitan or inner regional areas. Research to assess the psychometric properties of the short-form HDQ and EDQ for use in regional, rural and remote Australia is indicated, given that the management of episodic disability and its sequelae is a fundamental construct for people living with HIV. There is a need to address the concerning level of frailty, pre-frailty and disability found by this research and conduct future studies to explore interventions to limit the progression from pre-frailty to frailty, mitigate associated vulnerabilities and the adverse effect of disability on quality of life for people with HIV [54]. There are no existing rehabilitation programmes for people living with HIV in this outer regional area, mainly due to the low population and

lack of access to metropolitan-based rehabilitation services because of geographical isolation. Therefore, exploring the feasibility of a community-based programme that specifically considers the needs of outer regional, rural and remote Australian people living with HIV is recommended.

CONCLUSION

Disability, frailty and pre-frailty exist in adults with HIV in this regional Australian location. Thus, specific clinical and service needs require consideration and investigation. The HDQ demonstrated acceptable internal consistency, construct validity and test–retest reliability to independently measure disability and frailty in regional Australians with HIV. Future research should include a larger multi-centre study of disability and frailty, evaluate the psychometric properties of the HDQ short form and EDQ, and explore the implementation and evaluation of focused approaches to rehabilitation, considering the unique healthcare access challenges for regional, rural and remote Australians living with HIV.

AUTHOR CONTRIBUTIONS

Study conceptualization: CAF, MC, and KO; Data curation: CAF, MC, and RB; Formal analysis: MC and CAF; Investigation: PK, CAF, MC, and AJ; Project administration: CAF, PK, AJ, MC, and RB; Resources: CAF, PK, MC, and AJ; Software: MC and CAF; Supervision: CAF and KO; Validation: CAF, MC, AJ, RB, and KO; Visualisation: MC; Writing – original draft: CAF and MC; Writing – reviewing and editing: CAF, AJ, KO, MC, RB, and PK.

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CONFLICT OF INTEREST STATEMENT

Dr. Kelly K. O'Brien is one of the developers of the HIV Disability Questionnaire. She declares a personal non-financial potential conflict of researcher interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

Ethics approval for this study was obtained from the Townsville Hospital and Health Services, Queensland Health (HREC/QTHS/66818) and the James Cook University Human Ethics Committee (H8322).

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REFERENCES

- Trickey AP, Sabin CA, Burkholder G, et al. Life expectancy after 2015 of adults with HIV on long-term antiretroviral therapy in Europe and North America: a collaborative analysis of cohort studies. *Lancet HIV*. 2023;10(5):e295-e307.
- Sterne JAC, Sterne JAC, Hernán MA, et al. Long-term effectiveness of potent antiretroviral therapy in preventing AIDS and death: a prospective cohort study. *Lancet*. 2005;366(9483):378-384.
- Rajasuriar R, Wong PL. Disproportionate disability in people with HIV. *Lancet HIV*. 2023;10(3):e145-e146.
- Verheij E, Boyd A, Wit FW, et al. Long-term evolution of comorbidities and their disease burden in individuals with and without HIV as they age: analysis of the prospective AGEHIV cohort study. *Lancet HIV*. 2023;10(3):e164-e174.
- Samji H, Cescon A, Hogg RS, et al. Closing the gap: increases in life expectancy among treated HIV-positive individuals in the United States and Canada. *PLoS One*. 2013;8(12):e81355.
- Breen EC, Sehl ME, Shih R, et al. Accelerated aging with HIV begins at the time of initial HIV infection. *iScience*. 2023;26(8):1-27.
- Gobbens RJ, Luijckx KG, Wijnen-Sponselee MT, Schols JM. Toward a conceptual definition of frail community dwelling older people. *Nurs Outlook*. 2010;58(2):76-86.
- The Episodic Disabilities Network. Episodic disability toolkit of resources 2015: Canada. Accessed January 4, 2024. <https://episodicdisabilities.ca/docs/EpisodicDisabilityToolkitofResourcesFinal.pdf>
- O'Brien KK, Bayoumi AM, Strike C, Young NL, Davis AM. Exploring disability from the perspective of adults living with HIV/AIDS: development of a conceptual framework. *Health Qual Life Outcomes*. 2008;6(1):1-10.
- Fried LP, Tangen CM, Walston J, et al. Frailty in older adults: evidence for a phenotype. *J Gerontol A Biol Sci Med Sci*. 2001;56(3):M146-M156.
- Xue Q-L. The frailty syndrome: definition and natural history. *Clin Geriatr Med*. 2011;27(1):1-15.
- Bloch M. Frailty in people living with HIV. *AIDS Res Ther*. 2018;15(1):19.
- Somech J, Joshi A, Mancini R, et al. Comparison of questionnaire and performance-based physical frailty scales to predict survival and health-related quality of life in patients with heart failure. *J Am Heart Assoc*. 2023;12(6):1-10.
- Boettiger DC, Huque MH, Bloch M, et al. Physical function limitation among gay and bisexual men aged ≥ 55 years with and without HIV: findings from the Australian positive and peers longevity evaluation study (APPLES). *Sex Health*. 2022;19(6):533-545.
- Australian Government Department of Health, Disability and Ageing. Report for the Minister for Regional Health, Regional Communications and Local Government on the improvement of access, quality and distribution of allied health services in regional, rural and remote Australia 2020. 2020. Accessed January 4, 2024. <https://www.health.gov.au/resources/publications/final-report-improvement-of-access-quality-and-distribution-of-allied-health-services-in-regional-rural-and-remote-australia>
- Gilroy J, Dew A, Barton R, et al. Environmental and systemic challenges to delivering services for Aboriginal adults with a disability in Central Australia. *Disabil Rehabil*. 2021;43(20):2919-2929.
- O'Brien KK, Bayoumi AM, Strike C, Young NL, King EK, Solomon P. Reliability and validity of a new HIV-specific questionnaire with adults living with HIV in Canada and Ireland: the HIV Disability Questionnaire (HDQ). *Health Qual Life Outcomes*. 2015;13(1):124.
- O'Brien KK, Kietrys D, Galantino ML, et al. Reliability and validity of the HIV Disability Questionnaire (HDQ) with adults living with HIV in the United States. *J Int Assoc Provid AIDS Care*. 2019;18:1-10.
- Brown DA, Simmons B, Boffito M, et al. Evaluation of the psychometric properties of the HIV Disability Questionnaire among adults living with HIV in the United Kingdom: a cross-sectional self-report measurement study. *PLoS One*. 2019;14(7):1-17.
- Gagnier JJ, de Arruda GT, Terwee CB, Mokkink LB; Consensus Group. COSMIN reporting guideline for studies on measurement properties of patient-reported outcome measures: version 2.0. *Qual Life Res*. 2025;34(7):1901-1911.
- World Health Organization. *Measuring Health and Disability: Manual for WHO Disability Assessment Schedule (WHODAS 2.0)*. World Health Organization; 2010:1-152.
- Myezwa H, Hanass-Hancock J, Ajidahun AT, Carpenter B. Disability and health outcomes – from a cohort of people on long-term anti-retroviral therapy. *SAHARA J*. 2018;15(1):50-59.
- Debeaudrap P, Etoundi N, Tegbe J, et al. The association between HIV infection, disability and lifestyle activity among middle-aged and older adults: an analytical cross-sectional study in Ivory Coast (the VIRAGE study). *BMC Public Health*. 2024;24(1):1-13.
- Brown DA, O'Brien KK, Harding R, et al. Prevalence, severity, and risk factors of disability among adults living with HIV accessing routine outpatient HIV care in London, United Kingdom (UK): a cross-sectional self-report study. *PLoS One*. 2022;17(5):1-24.

25. Kietrys D, Myezwa H, Galantino ML, et al. Functional limitations and disability in persons living with HIV in South Africa and United States: similarities and differences. *J Int Assoc Provid AIDS Care*. 2019;18:1-9.
26. Oladejo TS, Myezwa H, Ajidahun AT, Ibeneme S. Prevalence and predictors of HIV-related disability among people living with HIV in Nigeria. *S Afr J Physiother*. 2024;80(1):2001-2008.
27. Barbosa KSS, Castro SS, Leite CF, Nacci FR, Accioly MF. Validation of the Brazilian version of the world health organization disability assessment schedule 2.0 for individuals with HIV/AIDS. *Cien Saude Colet*. 2020;25(3):837-844.
28. Morley JE, Malmstrom TK, Miller DK. Simple frailty questionnaire (FRAIL) predicts outcomes in middle aged African Americans. *J Nutr Health Aging*. 2012;16(7):601-608.
29. European AIDS Clinical Society. EACS guidelines. 2025. Accessed December 15, 2025. <https://eacs.sanfordguide.com/en/eacs-part2/eacs-part2-section8/managing-older-plwh>
30. Gardiner PA, Mishra GD, Dobson AJ. Validity and responsiveness of the FRAIL scale in a longitudinal cohort study of older Australian women. *J Am Med Dir Assoc*. 2015;16(9):781-783.
31. O'Brien K. *HIV Disability Questionnaire (version 10.5)*. University of Toronto; 2010:1-29.
32. O'Brien K. *Health Disability Questionnaire (HDQ) Administration and Scoring Manual*. McMaster University and the University of Toronto; 2017:1-29.
33. Australian Bureau of Statistics. Australian standard classification of cultural and ethnic groups (ASCEG). 2019. Accessed January 4, 2024. <https://www.abs.gov.au/statistics/classifications/australian-standard-classification-cultural-and-ethnic-groups-asceg/latest-release>
34. Landis JR, Koch GG. The measurement of observer agreement for categorical Data. *Biometrics*. 1977;33(1):159-174.
35. Terwee CB, Bot SD, de Boer MR, et al. Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol*. 2007;60(1):34-42.
36. Koo TK, Li MY. A guideline of selecting and reporting intraclass correlation coefficients for reliability research. *J Chiropr Med*. 2016;15(2):155-163.
37. Bonett DG. Sample size requirements for comparing two alpha coefficients. *Appl Psychol Measur*. 2003;27(1):72-74.
38. Woldemariam S, Oberndorfer M, Stein VK, Haider S, Dorner TE. Association between frailty and subsequent disability trajectories among older adults: a growth curve longitudinal analysis from the Survey of Health, Ageing and Retirement in Europe (2004-19). *Eur J Public Health*. 2024;34(6):1184-1191.
39. Australian Institute of Health and Welfare. Rural and remote health. 2025. Accessed January 26, 2026. <https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health>
40. Warner S, Cheung D, Condon A, et al. Communication and coordination of care for people living with HIV: a qualitative study of the patient perspective. *BMC Prim Care*. 2024;25(1):19.
41. Greene M, Justice AC, Lampiris HW, Valcour V. Management of human immunodeficiency virus infection in advanced age. *JAMA*. 2013;309(13):1397-1405.
42. Australian Institute of Health and Welfare. Older Australians. 2024. Accessed May 2, 2025. <https://www.aihw.gov.au/reports/older-people/older-australians>
43. Yamada Y, Kobayashi T, Condo A, et al. Prevalence of frailty and prefrailty in people with human immunodeficiency virus aged 50 or older: a systematic Review and meta-analysis. *Open Forum Infect Dis*. 2022;9(5):1-10.
44. Paolillo EW, Sun-Suslow N, Pasipanodya EC, et al. Pre-frailty predicts cognitive decline at 2-year follow-up in persons living with HIV. *J Neurovirol*. 2020;26(2):168-180.
45. Voigt N, Cho H, Schnall R. Supervised physical activity and improved functional capacity among adults living with HIV: a systematic Review. *J Assoc Nurses AIDS Care*. 2018;29(5):667-680.
46. Rubtsova AA, Marquine MJ, Depp C, et al. Psychosocial correlates of frailty among HIV-infected and HIV-uninfected adults. *Behav Med*. 2019;45(3):210-220.
47. Australian Government Department of Health. Future focused primary health care: Australia's Primary Health Care 10 Year Plan 2022-2032. 2022. Accessed May 2, 2025. <https://www.health.gov.au/sites/default/files/documents/2022/03/australia-s-primary-health-care-10-year-plan-2022-2032-future-focused-primary-health-care-australia-s-primary-health-care10-year-plan-2022-2032.pdf>
48. Vader K, Chan Carusone S, Aubry R, et al. Examining the utility of the HIV Disability Questionnaire (HDQ) in clinical practice: perspectives of people living with HIV and healthcare providers. *J Int Assoc Provid AIDS Care*. 2022;21:1-11.
49. O'Brien KK, Dzingina M, Harding R, et al. Developing a short-form version of the HIV Disability Questionnaire (SF-HDQ) for use in clinical practice: a Rasch analysis. *Health Qual Life Outcomes*. 2021;19(1):1-21.
50. O'Brien KK, Solomon P, Carusone SC, et al. Assessing the sensitivity and utility of a short-form version of the HIV Disability Questionnaire in clinical practice settings in Canada, Ireland and the USA: a mixed methods study. *BMJ Open*. 2022;12(9):1-14.
51. O'Brien KK, Erlandson KM, Brown DA, et al. Episodic disability questionnaire (EDQ) measurement properties among adults living with HIV in Canada, Ireland, United Kingdom, and United States. *BMC Infect Dis*. 2024;24(1):1-12.
52. UNAIDS. HIV_estimates_from_1990-to-2025. 2025. Accessed August 12, 2025. https://www.unaids.org/en/resources/documents/2025/HIV_estimates_with_uncertainty_bounds_1990-present
53. Centers for Disease Control and Prevention. Estimated HIV incidence and prevalence in the United States, 2018-2022. HIV surveillance supplemental report 2024. 2024. Accessed August 12, 2025. <https://stacks.cdc.gov/view/cdc/156513>
54. Keramat SA, Ahammed B, Mohammed A, et al. Disability, physical activity, and health-related quality of life in Australian adults: an investigation using 19 waves of a longitudinal cohort. *PLoS One*. 2022;17(5):1-17.

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