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Age, Cognitive Status and Accuracy of ADL Self-Reports in Adults Living with HIV

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Abstract

Determination of functional capacity in persons living with HIV (PLHIV) and cognitive impairment is pivotal to the accurate diagnosis of HIV-associated neurocognitive disorders (HAND). The typical method for collecting functional data is through self-report. Reliability concerns arise from potential age- and disease-related decrements in memory and executive functioning, which could compromise the integrity of self-report and increase the probability of inaccurate HAND diagnoses. The current study was designed to test the accuracy of older PLHIV functional reports through examination of concordance rates between self-report and caregiver's (CG) report. We hypothesized PLHIV participants would have high rates of discordant reports. Cross-sectional cognitive, mood and functional status data were sampled from the Manhattan HIV Brain Bank (MHBB). Participants and caregivers independently completed an Activities of Daily Living (ADL) questionnaire, producing 78 participant-caregiver dyads. Concordance of functional report was operationalized according to the score difference of the participant and CG ADL total scores. Assessment pairs differing by 2 or more points were considered discordant. Analyses revealed that one-third of the patient sample was discordant in ADL report. ANOVA revealed that PLHIV who overestimated their functional impairments were significantly older, more educated, and significantly more depressed than other participants in the other dyad groups. Global cognitive functioning was not associated with concordance. The data demonstrated that the majority of PLHIV were consistent with their caregivers' ADL report. Where reports differed, older age and increased depressive symptomatology, but not cognitive status, was associated with discordance.

Keywords

caregiving; functional status; HIV; PLHIV; activities of daily living

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Introduction

Determining the level of functional dependence in persons living with HIV (PLHIV) is an important component of comprehensive patient care and clinical research. Accurate assessment is critical to the diagnosis of HIV-Associated Neurocognitive Disorders (HAND), as levels of functional dependence, in the presence of cognitive impairment, determine the assignment of specific HAND diagnoses (Antinori et al., 2007). The standard method to determine functional status is self-report (Lawton & Brody, 1969; Tang & McCorkle, 2002).

Concerns over self-report accuracy have arisen for older PLHIV, because of their increased risk for age-related neurodegenerative disease and HIV-related cognitive decline, which may impair insight. Self-report reliability can also be compromised secondary to depression and reporting bias (Knowlton et al., 2015; Krug et al., 2010; Sneeuw, Sprangers, & Aaronson, 2002). Thus, empirical investigations of self-report validity are needed. However, no clear gold standard exists for evaluating functional self-report validity, leaving practitioners without guidance for the optimal choice of assessment. Two recent studies illustrated that a dual method approach, utilizing both self-report and performance-based measures, resulted in more accurate HAND diagnoses within viremically controlled PLHIV (Blackstone et al., 2012; Shirazi et al., 2017). However, the cost, equipment and degree of specialized expertise to support performance-based methods are not feasible for many settings. Informant reports are a cost-effective option.

Informant Reporting in HIV

Informal caregiving is commonly encountered in supportive networks for PLHIV, rendered by persons who provide emotional and/or “hands-on” services. Informal caregivers voluntarily provide care and typically have a personal relationship with the recipient (Mignone et al., 2015; Mitchell et al., 2015). For PLHIV, informal caregiving arrangements come from various types of intimate social relationships: marital, partnered, familial, neighbors, etc. (Moody, Morgello, Gerits, & Byrd, 2009). Given their close proximity, informal caregivers could constitute an important source of objective information about PLHIV.

Caregiver reporting accuracy can be influenced by factors such as the caregiver’s own functional ability, social network, psychiatric state and degree of caregiving-related stressors at the time of assessment (Mignone et al., 2015; Mitchell, 2014). Accuracy of caregivers’ reports may also depend on which functional domains are queried. For domains such as bathing, dressing and tracking appointments, studies show that caregivers’ reports accurately reflect patient reality, but for domains with more subjectivity—physical pain and perceptions of self-worth—caregivers tend to be less accurate (Krug et al., 2010). Thus, caregiver reporting is not absent of validity concerns. In the context of PLHIV, few studies have examined the utility and accuracy of informant reports of functional status. A primary contributor to this has been the inability to recruit large numbers of informants, partially due to the reticence of PLHIV in disclosing relationships, reflecting factors like social stigmatization and isolation (Shirazi et al., 2017). This is especially important for older males and people of color, who have smaller support networks and increased social isolation

(Emlet, 2006). However, two studies have contributed to what we understand about the value of informant report in the care of PLHIV. Kisakye et al., 2018 assessed the supplemental value of caregiver reporting in a sample of 324 persons with HIV who varied in their degree of cognitive impairment. They found that 77% of HIV+ dyads were concordant with lessening rates of concordance as severity of cognitive impairment increased. Murray et al. (2015) assessed caregivers' ability to identify key signs and symptoms for Minor Neurocognitive Disorder for 44 PLHIV. Findings were variable across the functional domains assessed but generally suggested that caregivers were uniquely positioned to accurately observe some symptoms that were undetected by PLHIV. In these studies, participants were relatively young and while there was considerable agreement in dyads, trends towards association between older-age and discordant reports were evident. Thus, for older PLHIV, at risk for neurocognitive decline and age-related neurodegeneration, the scope and form of their informants' support, and the reliability of their reports, has not been fully examined.

Study Objectives

The current study was designed to address gaps in the literature and advance understanding of the validity of functional status self-report. The aim was to measure the degree of functional status reporting concordance between PLHIV and their caregivers, and to test whether concordance varied according to clinical characteristics. Our study population generally exhibited advanced HIV disease, where greater variability in ADL status was expected; the population also had extensive clinical characterization, providing a unique opportunity for in-depth analyses of factors potentially associated with discordant functional status reports. We hypothesized that caregiver reports would be significantly concordant with participant self-report, and that participants with higher degrees of depressive symptomatology would be more likely to be discordant from their caregivers. Finally, we hypothesized that participants diagnosed with HAND would be more likely to have discordant reports than PLHIV without HAND.

Methods

Overview

Data for this study was collected by the Manhattan HIV Brain Bank (MHBB; U24MH100931), a longitudinal observational organ donation study with regular neurological, neuropsychological, medical, and psychiatric evaluations. MHBB eligibility requires willingness to be an organ donor upon demise, age ≥ 18 years, and significant medical disease burden, including: 1) diseases associated with advanced HIV infection; 2) CD4 T-cell count ≤ 50 cells/mm3; or 3) medical disorders without curative therapies.

This sub-study, the Manhattan Brain Bank Caregiver Study, had dual purposes. It was designed to procure proxy assessments of primary MHBB participants' functional abilities through an annual interview and questionnaire completion, and to enhance study staff contacts with informal caregivers, thereby potentially increasing likelihood of organ donation. The Caregiver Study was initiated in 2013, under a protocol approved by the Icahn School of Medicine Institutional Review Board (IRB). Eligibility criteria for caregivers included being 1) identified by an MHBB participant as a caregiver, 2) aged 18 years or older, and 3) English speaking. Caregivers were not required to know the HIV status of the participant. Two different IRB-approved consent forms were utilized based on caregivers' awareness of the participants' HIV status. Informed consent was provided by all participants and caregivers, who were reimbursed for their time.

Sample and Procedures

Seventy-eight MHBB participant-caregiver dyads participated in this study. Caregivers were interviewed privately, independent of MHBB counterparts. Caregivers completed the ADL scale, described below. MHBB participants completed a full neurobehavioral evaluation which included the ADL scale. Data was drawn from the baseline caregiver visit, and the corresponding MHBB participant study evaluation.

Measures

Neuropsychological test battery.—A comprehensive battery of neuropsychological tests measured the following cognitive domains in participants: learning, memory, information processing speed, fine motor speed, executive functioning, verbal fluency, and working memory (Woods et al, 2004).

Functional status.—A modified version of the Lawton and Brody Activities of Daily Living Questionnaire (Lawton & Brody, 1969) assessed self- and informant-report of the PLHIV's abilities. This 16-item scale total score range was from 0–16. On the caregiver version of the form, we collected information on the nature of the caregiving relationship, the length of time the caregiver had known the participant, and how often they communicated with each other. Upon completion of these questions, caregivers were asked to rate the MHBB participants' ADL capacity with the modified ADL instrument (ADL-CG).

Cognitive complaints.—Subjective cognitive complaints by PLHIV were measured with the Patient's Assessment of Own Functioning Inventory, a self-report measure with 33 items querying memory, language and communication, sensory-perceptual and motor skills, and higher-level cognitive functions (Chelune, Heaton, & Leham, 1986). Ratings on each item ranged from 1 (frequent difficulty with a task) to 6 (rarely experiencing difficulty with a task). Any item rated 3 or higher was considered an endorsement of difficulty and included as a point toward the total PAOFI score (range 0–33).

Depressive symptoms.—The Beck Depression Inventory, 2nd edition (BDI-II), is a 21 item self-report measure of depressive symptoms (Beck et al., 1996). Total scores range from 0–63, with higher scores indicating more severe symptomatology.

Cognitive status classifications.—HIV-associated neurocognitive disorders (HAND) were diagnosed according to Frascati criteria outlined in Antinori et al. (2007). Criteria for HIV-associated dementia (HAD) and Mild Neurocognitive Disorder (MND) required evidence of impairment in at least two cognitive domains and functional impairment with activities of daily living (ADL). Asymptomatic neurocognitive impairment (ANI) was diagnosed when cognitive impairment was observed without self-report of functional impairment.

Discrepancy classifications.—Caregiver-patient agreement was determined by total score differences on the ADL scale, and participants were classified into groups according to the degree and direction of total score difference from their caregiver. Total score differences that were ±1 point of each other were considered to be *Concordant*. Differences of ±2 points or greater were categorized as *Discordant*. Allowing one-point differences to be categorized as concordant recognized the small degree of variation likely to arise between two perspectives, particularly as most participants lived without the full-time assistance of caregivers. We wished not to over penalize participants for marginal differences in rating of functional ability. Furthermore, this threshold allowed for alignment with criteria for HAND, which requires “substantially greater assistance with more than two areas of daily living” (Antinori et al., 2007). Discordant dyads where the caregiver reported fewer functional deficits than the PLHIV were classified as *discordant-overestimate*. Dyads where the caregiver reported more functional deficits than the PLHIV were recognized as the *discordant-underestimate group*.

Laboratory values.—Blood samples were collected from MHBB participants for measurement of CD4+ T lymphocyte counts and plasma HIV RNA loads during their study visits.

Analyses

Bivariate correlations, Chi-square, paired t-tests, kappa statistics, and ANOVA were used in statistical analyses, performed with SPSS version 24 (IBM, New York). Predictors of dyad concordance type included: age, gender, education, cognitive status, depressive symptomatology, and subjective cognitive complaints.

Results

Participant demographics.

Demographic characteristics of participants and their caregivers are presented in Table 1. Most participants were male (65%), African-American (42%), had an average age of 56 years (M= 56.9; SD = 7.9, range 40 to 76), and mean education level of 12 years (M = 12.1; SD = 2.9, range 7 to 20). The caregiver group was also primarily male (66%), 49% African American and had an average age of 50 years (M= 50. 3; SD = 15.6, range 18 to 74 years). The most common relationship types were immediate or extended family (55.1%), with 24.4% of caregivers who were friends, and 20.5% classified as “other” (intimate partners, home health aides, clergy). Ninety-five percent of participants were on antiretroviral therapy, with median CD4 T-cell count of 521 cells/mm3 and median plasma viral load undetectable. HAND diagnoses were present in 47%, asymptomatic neurocognitive impairment (9%), mild neurocognitive impairment (13%), HIV associated dementia (4%), and neuropsychological impairment due to other causes (21%).

Caregiver/care recipient concordance.

The average self-report ADL score for MHBB participants was 2.2 (SD = 2.5, range 0–9). Forty-three percent (43.6%) of MHBB participants reported functional impairment in two or more domains. Twenty-four percent (24.3%) reported one area of difficulty and 32.1% had ADL scores of 0, denying any ADL difficulties. The average informant-report ADL score was 2.5 (SD = 3.1, range 0–10). Caregivers reported functional impairment in two or more domains for 47.5% of MHBB participants, in one domain for 17.9%, and scores of 0 for 34.6%.

Bivariate analyses revealed a significant moderate positive correlation between self- and informant-report of ADL scores (r = .70, p<.001). Median participant and caregiver total ADL scores were compared via a paired samples t-test. There was no significant difference between the total scores ($t(77) = -1.412$, p = .162). For the cohort, 65.4% (n = 51) were classified as *concordant.* Twenty-one percent (21.8 %, n = 17) were classified in the *discordant- underestimate* group. The remaining 12% (12.8, n = 10) were defined as *discordant- overestimate*. Thirty-nine percent (39.7%, n = 31) of the dyads were concordant with matching ADL scores.) Kappa statistics revealed a fair, but significant level of agreement (kappa .260, p <.001).

Age, gender and discrepancy group type.

ANOVA of group level demographic characteristics revealed a significant effect of participant age ($F(2, 75) = 4.20$, p = .02) and education ($F(2, 75) = 4.81$, p = .01; Table 2). Follow-up analyses revealed that discordant-overestimate participants were significantly older (M = 63.50; SD = 7.37) than the discordant-underestimate group (M = 55.71; SD = 6.13) and the concordant group (M = 56.08; SD = 8.16). The discordant-overestimate group were also more highly educated (M = 14.10; SD = 3.31) than the discordant-underestimate (M = 12.82; SD = 2.77), and concordant groups (M = 11.43; SD = 2.59). There was no significant difference in discrepancy group classification based on gender [χ^2 (2, 78) = .256, p =.88].

Cognitive complaints, depression, HAND diagnosis, and discrepancy group.

We compared the degree of current cognitive complaints (PAOFI) between participants in the discrepancy groups (Table 2). ANOVA revealed a significant effect of group type on cognitive complaints (F (2, 70) = 7.5, p < .01). The discordant-overestimate group reported significantly higher PAOFI scores (M = 10.56; SD = 7.99) than the concordant (M = 3.94; SD = 4.67) and discordant-underestimate groups (M = 3.07; SD = 3.65). To determine the impact of current depressive symptomatology on discordant reports of functional status, we compared BDI-II scores across discrepancy groups (Table 2). ANOVA revealed significance (F (2, 75) = 7.20, p <.01). The discordant-overestimate participants endorsed more depressive symptomatology (M = 17.60; SD = 9.86) compared to the discordant-underestimate group (M = 11.18; SD = 6.37) and concordant group (M = 7.71; SD = 7.72). A Chi-square analysis compared the frequency of discordant classification with the presence or absence of HAND (HAD, MCMD and ANI combined). Results were not significant (χ^2 (1, N = 78) = .256, p =.157). A qualitative exploration to determine whether a different diagnostic decision would have been rendered for participants with ANI if the caregiver rating was used in place of self-report was done; this exploration revealed that only one PLHIV would have received a diagnosis of MND.

Discussion

The current study was designed to advance understanding of the validity of functional status self-reports given by PLHIV, measuring concordance with their caregivers' reports. Two- thirds of MHBB participant reports were concordant with their caregivers, consistent with other publications examining caregiver/self-report concordance for PLHIV (Kisakye et al., 2018; Murray et al., 2015). The discordant-overestimate group who overreported ADL dependence had higher degrees of depressive symptomatology. This may suggest that symptoms of depression are associated with exaggerated self-perceptions of functional disability, and negative self-schema are documented with depression (Thames et al., 2011). This suggests a need for greater effort to confirm functional disability when self-reported from persons experiencing acute depressive symptoms.

Interestingly, the discordant-overestimate group were the oldest and most educated portion in our sample, consistent with one prior study demonstrating association between aging and perceived decline, concurrent with depressive symptomatology (Yates, 2020). However, other literature is contradictory, as another study documented fewer cognitive complaints and functional difficulties in older educated participants compared to less educated ones (Lee, Sung, and Choi, 2020). Our findings suggests that more educated PLHIV, with more cognitive reserve, might be more sensitive to declining performance. Future research should examine how education influences participant subjective complaints.

Finally, our hypothesis that PLHIV with HAND would be more likely to be discordant, due to increased potential for compromised insight, was not supported. This contrasts with a prior study in which cognitively impaired PLHIV were more discordant with caregivers than those who were cognitively normal (Kisakye et al., 2018). A lack of relationship between report discordance and HAND in our dyads suggests that disability self-report may not require external validation for PLHIV with HAND, unlike the common practice for age-related dementias. We were especially interested in the concordance of persons with ANI, since this category of HAND is notable for the absence of functional impairment despite cognitive dysfunction, but were not powered to do so in this sample (Antinori et al, 2007). Nonetheless, exploratory analyses indicated that this group was not more likely to have discordant reports of ADL status.

Strengths

The current study had several strengths. The demographic composition of our sample adds greater age and ethnic diversity to the literature, increases generalizability of findings, and counters the underrepresentation of ethnic minorities in scientific HIV literature (Knowlton, 2003). We used comprehensive cognitive protocols in HAND classification, which relative to screening, provided greater confidence in inferences about the relationship between cognitive impairment and discordant reporting patterns.

The use of a comprehensive operational definition for caregivers allowed us to thoroughly reflect the full social support spectrum of PLHIV. Research with PLHIV caregivers is often restricted to narrowly defined, predetermined roles of family-relatedness or romantic partnering, and may exclude nontraditional care support systems. This is especially important for LGBTQ ethnic minority PLHIV, whose family dynamics are often complex with concepts of family extending beyond blood relatives. In allowing patients to self-identify who served in these roles, we were afforded a holistic and representative sample of dyads. Half of our study's caregivers were extended family, friends, and other relations; a significant percentage compared to other studies in HIV caregiving literature, where immediate family members could account for over 60% of samples reported (Mitchell et al., 2015; Kisakye et al., 2018).

Limitations

We did not collect caregiver education levels, HIV status or mental health symptomatology, and could not explore hypotheses related to the influence of demographic similarity or dissimilarity among dyads. Past studies suggest HIV-positive caregivers for PLHIV empathize with the care recipient's condition, influencing perception of mastery for disease-specific tasks such as medication adherence (Mitchell 2014; Knowlton et al, 2015). Also, caregiver burden was not assessed in the current study (Miller et al., 2013; Sprangers & Aronson, 1992). Finally, our sample size was a limitation. Of 170 active MHBB participants, more than half were excluded due to a lack of a caregiver or caregiver unavailability. Further, some of our group sizes were small and limit the generalizability of findings from these groups.

Conclusion

Our preliminary findings suggest that MHBB participants are able to accurately report their functionality, and that caregiver report is a reliable, cost-efficient method to validate participant self-report. Furthermore, depressive symptomatology should be considered as it may influence self-report.

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Table 1

Participant Demographics and Characteristics

	Caregivers (N = 78)	**PLHIV (N=78)**
Mean Age years; (SD; Range)	50.3 (15.6; 18–74)	56.9 (7.9; 40–76)
Education years (SD; Range)	--	12.08 (2.9; 7–20)
Female; n (%)	26 (33.3)	24 (34.6)
Race/Ethnicity; n (%)		
Black/African American	37 (48.7)	33 (42.3)
Hispanic	20 (25.6)	24 (30.8)
White	19 (24.4)	17 (21.8)
Mixed	1 (1.3)	4 (5.1)
American Indian/Alaska Native	1 (1.3)	
HIV Characteristics		
Median CD4 (Range)	--	521 cells/mm3 (23–1713)
Median Viral Load (Range)	--	20 copies/ml [*] (20–352,530)
Duration on MHBB study at time of caregiver interview (months)		
0–60; n (%)	--	32 (41.0)
60–120; n (%)	--	34 (43.6)
120+; n (%)	--	12 (15.4)
Caregiver Relationship Types n (%)		
Immediate or Extended Family [*]	43 (55.1)	
Friends	19 (24.4)	
Other	16 (20.5)	

[*] Immediate family = mother, father, spouse, children, siblings; Extended family = niece, nephew, uncle, cousin; Other = home health aide, partner

[*] Limits of detection for assay 20 copies/ml

Table 2

Clinical Characteristics Based on Discrepancy Group

	Concordant (n = 51)	**Discordant-Underestimate (n = 17)**	**Discordant-Overestimate (n = 10)**	**p value**	**η2**
	Mean (SD) or %	**Mean (SD) or %**	**Mean (SD) or %**		
Age	56.1 (8.20)	55.7 (6.1)	63.5 (7.4)	.02	.101
Female	41.2%	41.2%	70.0%	--	
Education	11.4 (2.59)	12.8 (2.77)	14.1 (3.32)	.01	.114
PAOFI *	3.94 (4.67)	3.07 (3.65)	10.56 (7.99)	.001	.179
HAND diagnosis *	22 (43.1%)	10 (58.8 %)	5 (50.0%)	--	
BDI-II *	7.71 (7.72)	11.18 (6.37)	17.60 (9.86)	.001	.161

[*] PAOFI = Patient Assessment of Own Functioning Inventory, N = 73, missing 5 cases; HAND = HIV Associated Neurocognitive Disorder; BDI = Beck Depression Inventory-II