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CAREGIVER VERSUS SELF-REPORTED ACTIVITIES OF DAILY LIVING AMONG HIV-POSITIVE PERSONS IN RAKAI, UGANDA.

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Abstract

Assessment of an individual's functional status, as measured by activities of daily living (ADL), is an essential element in the diagnosis of HIV-associated neurocognitive disorders (HAND) but individuals with cognitive impairment may not accurately report ADL. We assessed agreement between self- and caregiver-reported ADL in HIV-positive persons. Antiretroviral therapy (ART)-naïve HIV-positive persons (n=321) and HIV-negative controls (n=134) in Rakai, Uganda, completed neurocognitive tests and an ADL questionnaire. Co-resident relatives ("caregivers") were independently administered the ADL questionnaire to determine their perception of the participant's ADL. The relationship between neurocognitive impairment and participant-caregiver agreement was assessed using kappa statistics. Regression was used to estimate adjusted prevalence ratios (AdjPR) of participant-caregiver agreement on disability scores. Relative to HIV-negative adults, HIV-positive participants scoring at least 1 standard deviation (SD) below the norm on 2 or more neurocognitive tests were classified as having mild neurocognitive impairment and those scoring at least 2 SD below the norm on 2 or more neurocognitive tests were classified as having moderate-to-severe

Mean age was 36 years (SD 8.9), and 53% of participants were male. The rate of ADL agreement between participants and caregivers was 77% for HIV-positive and 87% for HIV-negative participants (AdjPR= 0.89, 95% CI 0.81- 0.97, p=0.01). Among HIV-positive participants, 41% had moderate neurocognitive impairment, 15% had severe neurocognitive impairment, and 44% were normal. For moderate neurocognitive impairment, the rate of ADL agreement was 69% and for severe neurocognitive impairment it was 66%. Compared to non-impaired HIV-positive participants (86% ADL agreement), ADL agreement was lower with moderate impairment (AdjPR=0.89, 95% CI 0.81-0.98, p=0.023) and severe impairment (AdjPR=0.77, 95% CI 0.63-0.95, p=0.014). Gender, education and CD4 count were not associated with ADL agreement.

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Conflict of Interest

All authors did not have any conflicts of interest.

HIV-positive persons with neurocognitive impairment have lower agreement with caregivers' reports of ADL than HIV-positive persons without cognitive impairment.

Keywords

Activities of Daily living; Care giver; self-reports; neurocognitive impairment; agreement

INTRODUCTION

HIV-associated neurocognitive disorders (HAND) are defined by neurocognitive and functional status impairments such as limitations in performing activities of daily living (ADL).² Self-reported ADL are widely used in clinical settings because they are inexpensive and easy to administer but may be less accurate in persons with neurocognitive impairment (Howland M, Allan KC, Carlton CE, Tatsuoaka C, Smyth KA, 2017). Performance-based ADL may be more accurate (Gandhi, Skolasky, Peters, Moxley, Creighton, Roosa, Selnes, McArthur, & Sacktor, 2011a) but requires more time, expertise and expense (Blackstone et al., 2012; Shirazi et al., 2017). Use of caregiver reports of ADL among HIV-positive patients with neurocognitive impairment has not been studied. (Gandhi, Skolasky, Peters, Moxley, Creighton, Roosa, Selnes, McArthur, Sacktor, et al., 2011)

We evaluated the concordance of self-reported versus caregiver-reported ADL in HIV-positive and HIV-negative adults in rural Rakai, Uganda.

METHODS

Participants underwent a detailed medical and neurological history and examination and completed a battery of neurocognitive tests (Kevin R Robertson, Noeline Nakasujja, 2007) in Rakai, Uganda. Participants identified a caregiver residing in the same house as them and acquainted with their daily activities (e.g. spouse, adult children,). All participants completed a 15-question questionnaire on Instrumental Activities of Daily Living (Fieo R, Watson R, Deary IJ, 2010) administered in Luganda, the local language. Caregivers completed the same questionnaire assessing the participant's ADL. All participants provided written informed consent for study participation and to have their caregiver contacted. Enrolment was conducted between July 2013 and July 2015. Human Subjects review and approval were provided by the Research and Ethics Committee of Uganda Virus Research Institute, the Uganda National Council of Science and Technology, and Western Institutional Review Board (Olympia, WA).

Three hundred and twenty-one HIV-positive and 134 HIV-negative participants had paired caregiver ADL responses, and analysis was limited to these pairs. Neurocognitive status in HIV-positive participants was classified as mild impairment for those who scored at least 1 standard deviation (SD) below the mean on 2 or more neurocognitive tests, and as moderate-to-severe for participants who scored at least 2 SD below the mean on 2 or more neurocognitive tests. The ADL questions were scored as 0 (no difficulty) 3 (severe).

We analysed percent agreement by comparing maximum disability response on any item given by the participant with that of the caregiver. Participants who had the same maximum ADL score as their caregiver were concordant, while those who had a differing maximum ADL score from their caregiver were considered discordant. Agreement was assessed using kappa statistics and chi square tests. Modified Poisson regression with robust variance was used to estimate the prevalence ratios (PRs) and 95% confidence intervals (95%CI) of the association of agreement between self and caregiver by HIV status, diagnosis of neurocognitive impairment, sex, age, education, and CD4 count. The rationale for using modified Poisson regression rather than logistic regression and odds ratios was that odds ratios are frequently misinterpreted as relative risks but do not approximate to relative risk when the outcome frequency is greater than 10% (Norton, Dowd, & Maciejewski, 2018). Stata 14 (College Station, TX) was used for analysis.

RESULTS

Of 455 participants, 71% (n=321) were ART-naïve HIV-positive adults, and 53% were males (n=241). Average age was 36 (SD 8.6) years among HIV-positive participants and 38 (SD 9.4) years among HIV-negative participants. Most participants (80%) had < 8 years of education. Among HIV-positive participants, 48% (n=155) had a CD4 count < 200 cells/ul and 52% (n=166) had a CD4 cell count between 350-500 cells/ul. (NB: the Ugandan national guidelines called for ART initiation at CD4 350 at the time of the study. All participants with CD4 below 350 were immediately referred for free ART services; this was before the introduction of test and treat.) Mild neurocognitive impairment was found in 41% (n=131) of HIV-positive participants and 44% (n=59) of HIV-negative participants. Moderate-to-severe impairment was diagnosed in 15% (n=49) of HIV-positive and 4.5% (n=6) of HIV-negative participants.

Percent agreement for the maximum disability scores among HIV-positive participants and their caregivers was 77% (kappa 0.32, $p < 0.001$), and among HIV-negative participants, 87% (kappa 0.316, $p < 0.001$) (Table 2). Among HIV-positive participants, the percent agreement in those with mild neurocognitive impairment was 69% (kappa 0.28, $p < 0.001$) and with moderate-to-severe neurocognitive impairment, agreement was 66% (kappa 0.36, $p = 0.0001$). Those with no neurocognitive impairment had 86% agreement with their caregivers (kappa 0.36, $p < 0.001$).

Adjusted prevalence ratio of agreement was significantly lower among HIV-positive compared to HIV-negative persons (AdjPR = 0.89, 95% CI 0.81-0.97, $p = 0.01$) (Table 3). Participants with mild neurocognitive impairment had significantly lower agreement compared to unimpaired participants (AdjPR = 0.89 (0.81- 0.98, $p = 0.023$) as did those with moderate-to-severe neurocognitive impairment (AdjPR = 0.77, 95% CI 0.63-0.95, $p = 0.014$). The prevalence ratios of agreement associated with gender, CD4 and education were not statistically significant. However, each year of increasing age was associated with significantly reduced participant-caregiver agreement (AdjPR = 0.99, 95% CI 0.99-1.00, $p = 0.034$). As shown in Table 4, among discordant pairs, there was no significant difference in participant under- or over-reporting disability compared to the caregiver's report in neurocognitive impairment relative to unimpaired participants

DISCUSSION

Neurocognitive disorders in HIV-positive persons may reduce ART adherence with deleterious effects on HIV viral load suppression and immunological status (Fogarty et al., 2002; Gross, n.d.; Hinkin et al., 2002). Therefore, diagnosing HAND is important in order to identify patients who may need more intensive support services to optimally manage their HIV infection. Determining HAND stage using the Frascati criteria (Antinori et al., 2007), requires accurate assessment of ADL for a precise diagnosis of HAND stage.

However, the best way to assess ADL is not known: self-reports, one of the most commonly used assessment methods in clinical settings, may be affected by self-perception bias and presence of neurocognitive impairment (Howland M, Allan KC, Carlton CE, Tatsuoka C, Smyth KA, 2017; Shirazi et al., 2017). Performance-based direct observation of ADL provide a more objective measure of functionality (HEATON et al., 2004) and a study using two performance-based tests (Columbia Medication Management Test and San Diego Finances Test) showed both of these tests were useful in predicting the HAND stages (Gandhi, Skolasky, Peters, Moxley, Creighton, Roosa, Selnes, McArthur, & Sacktor, 2011b). However, these tests were time consuming, required expertise and were expensive.

Studies on cognitive impairment and Alzheimer disease suggest differences in patients' and caregivers' reports on patients' functionality depending on the level of impairment (Graham DP, Kunik ME, Doody R, 2005; Ready & Ott, 2008; Snow et al., 2005). One study demonstrated that caregivers of cognitively impaired patients provided more accurate information than both the patients and clinicians' assessments (Ready & Ott, 2008). Therefore, independent caregiver's reports of ADL among HIV-positive persons may provide a more objective measure of ADL, but this has not been previously assessed. (Gandhi, Skolasky, Peters, Moxley, Creighton, Roosa, Selnes, McArthur, & Sacktor, 2011a)

The main findings of this study were that HIV-positive persons with neurocognitive impairment were more likely to have discordant reports of ADL relative to their caregivers' reports than were neurocognitively normal and HIV-negative participants. There was no clear pattern of participants' over- or under-reporting limitations of ADL relative to their caregivers' reports. This differs from a prior study that found patients with dementia were likely to under-report disability compared to family caregivers (Snow et al., 2005), possibly due to reduced awareness of deficits among patients (Graham DP, Kunik ME, Doody R, 2005). However, the higher rates of discordant ADL reports from participants with neurocognitive impairment suggest that further investigation is needed to determine the reasons for the discordant reports. Despite the higher discordance rates between neurocognitively impaired participants and caregivers, there was no clear patterns of participants under- or over-reporting deficits compared to caregivers. Further studies are needed to determine whether interviewing caregivers of neurocognitively impaired patients may provide more accurate assessment of ADL and more accurate HAND staging.

The main limitations of the study were the lack of information on duration of the caregiver's involvement with the participants as well as basic demographic information about the caregiver. Therefore, we could not assess whether these caregiver-associated factors affected

agreement between participant and caregiver ADL reports. Future studies examining the influence of caregiver factors on agreement of ADL reports are needed. Also, we did not assess psychosocial factors such as mood and anxiety disorders or socioeconomic difficulties which have been associated with neurocognitive impairment (Laverick et al., 2017).

CONCLUSION

HIV-positive persons with moderate to severe neurocognitive impairment have higher rates of discordant ADL reports relative to their caregivers. Interviewing a patient's caregiver regarding the patient's ability to complete ADL may provide more accurate information about functional status limitations than patient self-report, especially in HIV-positive persons with neurocognitive impairment, which may then result in more accurate HAND staging in this population.

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Table 1:

Participants' characteristics

HIV status	HIV-POSITIVE (percentage/mean)	HIV- (percentage/mean)	P value
N	321(71%)	134(29%)	
Mean Age	35.7	38.4	0.06
CD4 counts			
<200	155 (48.3%)		
350-500	166 (51.7%)		
Males	72 (53.7%)	169 (52.7%)	0.83
Females	62 (46.3%)	152 (47.3%)	
Neuropsychological Impairment			
None	141 (43.9%)	69 (51.5%)	
Moderate	131 (40.8%)	59 (44.0%)	0.005
Severe	49 (15.3%)	6 (4.5%)	
Years of education			
0-4	143 (44.5%)	60 (44.8%)	0.048
5-7	117 (36.7%)	42 (31.3%)	
8-11	50 (15.6%)	19 (14.2%)	
12-17	11 (3.4%)	13 (9.7%)	

Table 2:

Kappa statistic and percent agreement

	Kappa statistic	% agreement	P value
All pairs	0.3252	79.6%	<0.001
HIV-positive	0.3227	76.6%	<0.001
HIV-negative	0.3061	86.6%	<0.001
No neuropsychological impairment	0.3634	86.2%	<0.001
Moderate impairment	0.2750	69.4%	<0.001
Severe impairment	0.3581	65.5%	0.0001

Table 3.

Univariate and multivariate Poisson regression of discordance between participant and caregiver reports of ADL.

characteristic	Unadjusted Prevalence ratios (95% CI)	P value	Adjusted prevalence ratios (95% CI)	P value
HIV-POSITIVE vs HIV-	0.89 (0.81-0.97)	0.008	0.89 (0.81- 0 .97)	0.010
female vs male	0.96 (0.85-1.08)	0.514	0.93 (0.84 - 1.02)	0.105
Age (years)	1.00 (0.99-1.00)	0.239	0.99 (0.99 -1.00)	0.034
Impairment categories:				
	0.89 (0.80 - 0 .97)	0.013	0.89 (0 .81- 0 .98)	0.023
Moderate vs normal				
	0.75 (0.62 - 0 .93)	0.007	0.77 (0.63 - 0 .95)	0.014
Severe vs normal				
CD4	0.94 (0.83- 1.0)	0.321	0.96 (0.84 - 1.08)	0.476
Education:				
5-7 years	1.12 (0.98 - 1.27)	0.095	1.03 (0.93 - 1.14)	0.583
8-11 years	1.00 (0.83 - 1.22)	0.937	0.91 (0.79 - 1.07)	0.273
12-17 years	0.99 (0.68 - 1.44)	0.960	0.94 (0.77 - 1.15)	0.547

Table 4.

Comparison of Percentage discordant participant-caregiver pairs under and over reporting ADL

category	under reporting (%)	over reporting (%)	P value
Unimpaired	42	58	
Moderate impairment	52	48	0.51
Severe impairment	60	40	0.30