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VATA-ADL

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VATA-ADL:

The Visual Analogue Test for Anosognosia for Activities of Daily Living

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Abstract

Objective. To study awareness of problems with one's own Activities of Daily Living following stroke by means of a novel instrument, the Visual-Analogue Test for Anosognosia for Activities of Daily Living (VATA-ADL).

Methods. The new test overcomes some of the methodological problems of traditional structured interviews and self-rating questionnaires. In particular, to account for possible verbal communication difficulties, each question is illustrated by a drawing and a 4-point visual-analogue Likert scale. The patient's self-rating is compared with that given by informants (personal or professional caregiver) to acquire a measure of metacognition of one's own problems in performing everyday tasks.

Results. The VATA-ADL was validated in 61 dyads of older people and their informants. A group of 80 post-acute stroke patients and their informants then completed the test. Informant ratings correlated highly with traditional ADL scales, the questionnaire items showed high internal consistency ($\alpha = .95$) and loaded onto one factor. By comparison to informants' assessments, the patients showed a generally poor appreciation of their functional disabilities. Thirty-nine patients overestimated their abilities (anosognosia) whereas nine showed underestimation of their abilities.

Conclusions. Anosognosia (overestimation of abilities) for ADL is frequent, even in post-acute stages post-stroke. Some other patients underestimated their abilities, indicating that poor metacognition of one's own abilities in brain damaged patients is bi-directional. Both types of misestimation may have clinical consequences worth considering for the wellbeing of patients and their carers.

Keywords: Anosognosia, Unawareness, ADL/iADL, Stroke, Assessment

Introduction

Clinicians routinely check for patients' behavioural competence in daily living, relying on clinical interviews labelled "Activities of Daily Living" (ADL) (Katz, Ford, Moskowitz, Jackson & Jaffe, 1963; Mahoney, 1965) or instrumental ADL (iADL; Lawton and Brody, 1969; Chong, 1995). These scales have well–established validity (Brorsson & Asberg, 1983; Collin, Wade, Davies & Horne, 2009) and are based on either self-report or informant-report (Gold, 2012). Most of these scales are designed to assess frail older people or people with pathological ageing. Whereas healthy older people show little to no problems with ADL or iADL, those affected by dementia (Gold, 2012) or stroke (Chong, 1995) ultimately show pronounced impairments with both. Awareness for specific abilities (e.g., motor, language, memory, attention, etc.) has been often investigated (e.g, Prigatano, 2010); however, awareness of one's own ADL impairments is rarely measured, although a lack of awareness (anosognosia; Mograbi & Morris, 2018) of having impairments in ADL could be important for the patients' management and well-being (Prigatano & Morrone-Strupinsky, 2010).

Unawareness of ongoing functional problems has received surprisingly little attention in the stroke literature, perhaps because anosognosia is thought to resolve in the acute stages after a stroke (Jehkonen, Ahonen, Dastidar, Laippala & Vilkki, 2000; Starkstein, Jorge & Robinson, 2010). Yet, there have been sufficient cases of post-acute anosognosia reported in the literature to show that it is not an exclusively acute stage phenomenon (Cocchini, Beschin & Della Sala, 2002, review in Orfei et al. 2007). It is therefore important to determine if patients have long term poor awareness of their limitations in daily activities.

The main goal of the current study is to report on the development of the Visual-Analogue Test for Anosognosia for Activities of Daily Living (VATA-ADL), a measure assessing awareness of one's own daily activities difficulties. We also report a study examining awareness for daily activities using this scale in a group of patients in the post-acute phase following a stroke.

The VATA-ADL assesses explicit awareness of possible difficulties in a variety of everyday situations. There are currently four VATA scales: the VATAm assesses anosognosia for motor impairments (Della Sala, Cocchini, Beschin & Cameron, 2009);

the VATA-L assesses anosognosia for language impairments (Cocchini, Gregg, Beschin, Dean & Della Sala, 2010); the VATAmem (Chapman et al., 2019) assesses anosognosia for memory deficits; and the VATA-NAT aims at assessing anosognosia for apraxia for tool use (Buchmann et al., 2018).

These VATA assessments all share common design features. A series of questions about a patient's potential disabilities are presented in a format designed to be broadly accessible. Each question is illustrated with a visual vignette (Clare et al., 2012), and requires a response on a four-point visual analogue Likert scale. This allows for the testing of patients with verbal communication difficulties, who cannot be tested with traditional questionnaires. The simple depictive format also minimises memory and attentional load due to long instructions, allowing for the testing of patients with memory and attention impairments. Each test includes check questions, requiring obvious answers, which serve to screen out unreliable respondents. The test is administered in a first-person format to patients and a third-person format to informants who know them well (e.g., family members or professional carers), providing the basis for the assessment of awareness (Cocchini, Beschin & Della Sala, 2012).

Given that informant-reports are considered to provide reasonably accurate appraisals of functional ability (Gold, 2012), one viable method of measuring awareness is to calculate the discrepancy between patient-rated and informant-rated scores (Debettignies, Mahurin & Pirozzolo, 1990; Tabert et al., 2002; Della Sala et al., 2009). This discrepancy-method is the principle upon which the VATA format was originally devised (Della Sala et al., 2009). Informant scores are taken to represent actual disability, and the discrepancy between self- and informant-ratings thereby provides a measure of the accuracy of self-assessment, and thus of awareness of disability.

In developing the novel VATA-ADL scale, the requirements were that it should: (i) be suitable for administration to patients and informants; (ii) provide a valid measure of the ability to carry out activities of daily living; and (iii) provide a measure of awareness of one's own functional disability. The purpose of this study is to present a novel tool, the VATA-ADL scale, to allow the assessment of awareness of one's own ability for ADL in people suffering from neurological damage. For the tool to provide a valid assessment of awareness of ADL in people with neurological damage,

it must first be validated as a measure of ADL activities that people without such damage can normally manage. To this aim, we will first report on a validation of the scale items with a group of healthy older adults, likely to be in the same age range as the target population for the awareness scale (Study 1). Second, we will report on the awareness of one's own ADL problems using this instrument in a group of stroke patients (Study 2). These studies are conducted with the aim of taking initial steps to establish the VATA-ADL as a valid research tool, though they would not be sufficient to fully validate this novel method

Methods

All participants, patients, and informants who took part in the various phases of the study gave their informed written consent. The study was approved by the relevant Research Ethical Committee of the University of Edinburgh.

VATA-ADL piloting

The VATA-ADL was developed through a series of pilot studies that allowed us to refine the vignettes/questions based on the feedback received at each step. An initial set of 24 questions and vignettes was piloted with two sequential groups of young, healthy, English speaking volunteers. This initial set of activities was based loosely upon the activities listed in the Nottingham Extended Activities of Daily Living Scale (NEADL - Nouri & Lincoln, 1987). No items related to housework or DIY were included to minimise gender bias. A sample of 39 participants in the first group (32 women; mean age 19.10 years; SD= 0.86) were asked to describe the action depicted in the vignettes. As a result, five vignettes were completely redrawn and further three amended to avoid potential ambiguities. A second group of 54 participants (44 women; mean age 18.87 years; SD= 1.73) were asked to describe the revised set of vignettes/questions. Their response for each vignette was compared with its intended meaning and was rated from 1 (description matched intended meaning) to 4 (description different from intended meaning). This allowed us to select the most consistently interpreted 22 vignettes/questions where on average 97% (SD= 0.04; range 91%-100%) of the participants' response was rated either 1 or 2. An additional vignette/question was selected as a practice item.

VATA-ADL: Material and methods

The final version of the VATA-ADL comprises 23 questions illustrated in simple vignettes. The list of all questions is provided in Table 1. Of the 23 questions, one is used as a practice item to ensure understanding of the task, and 4 are check questions (described below). The remaining 18 items enquire about the participant's ability to perform everyday activities involving self-care (6 questions; e.g., taking a bath or shower), activities that are usually performed inside the house (6 questions; e.g., watering plants), and activities that are usually performed outside the house (6 questions; e.g., getting in and out of the car; see Table 1). Figure 1 depicts some examples of the vignettes included in the VATA-ADL. The full test is freely available[1].

--- Insert Table 1 and Figure 1 about there ---

VATA-ADL is administered to patients in the presence of the examiner in the form of a 23-page booklet, with one vignette per page, in a fixed pseudo-random order. The informant completes the test on their own accord. Items are presented one per page. The question, 'Would you have difficulty…?' appears at the top of each page with a large vignette (half a page) illustrating the activity immediately underneath.

Often patients had no opportunity to directly experience a difficulty (e.g., driving a car) as the attempt to perform some tasks may represent a potentially dangerous situation (D'Imperio, Bulgarelli, Bertagnoli, Avesani & Moro, 2017) or they rarely engaged with the task depicted even before the stroke. However, lack of direct experience does not prevent some patients to become aware of the complexity of their situation. For example, aware hemiplegic patients do not need to attempt driving a car to be aware of the limitations they would face in performing this task. For this reason, the questions were formulated as "Would/Do you..." rather than "Do you..." Moreover, we were interested in assessing the patient's perceived capabilities, i.e., what the patients believe they could do rather than running the risk of tapping event memory about past failures.

Participants are required to rate themselves (or the person they are informing on) for *current* ability in each of the tasks depicted by the vignettes, using a visual

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[1] The test is freely available for downloading in several languages from https://www.ed.ac.uk/profile/sergio-della-sala, under Tests > VATA-ADL

analogue response scale displayed at the bottom of the page. At each extreme end of the scale, there are drawings of smiling and neutral faces and the scale contains four points representing increasing levels of difficulty, from 0 ('No Problem') to 3 ('Problem'). Hence, the total possible score for the 18-target items ranges from 0 to 54, where higher ratings indicate greater difficulties. Patients indicate responses by saying out aloud the number or by pointing to a specific point on the scale (Della Sala et al., 2009; Cocchini et al., 2010).

Similar to other VATA scales (Della Sala et al., 2009; Cocchini et al., 2010; Chapman et al., 2019), four check questions were included to ensure understanding of and compliance with the test. Two of these (i.e., hearing a loudspeaker; recognising yourself in the mirror) were designed to be achievable by most people, regardless of their cognitive abilities. The expected difficulty rating for these control items was 0 or 1. Two other check questions (i.e., pulling a lorry; swinging on a trapeze) were designed to be unachievable by most people.[2] The expected difficulty rating for these items was either 2 or 3. Ratings from the four check questions were used only to monitor reliability of the participant's responses, allowing the exclusion of participants giving unexpected (i.e., out-of-range) responses to any check question.

Informants rated the participants' potential problem to perform each task using the same items with the question wording cast in the third person. As for the participants, the check questions were used to monitor response reliability and not included in the final total VATA-ADL score, which was calculated considering the 18-target items with a score range from 0 (no difficulty in any task) to 54 (max difficulty in all tasks).

A discrepancy score was then obtained by subtracting the participant's total score from the informant's total score. A discrepancy score could theoretically range from -54 to +54, where a value of 0 indicated complete agreement between participant and informant. A positive discrepancy score indicates that, compared with the informant's ratings, the participant overestimated his/her own skills, whereas a negative discrepancy indicates that the participant underestimated his/her own skills.

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[2] A check question should be disregarded if the participants' ability to perform the task is affected by associated difficulties (e.g., deafness for the 'Hearing a loudspeaker' question) or specific abilities (e.g., having been an acrobat for the 'Swinging on a trapeze' question).

VATA-ADL – Study 1: Validation with older people

This study pertains to the validation of the VATA-ADL items as a measure of ADL, which is necessary for it to provide the basis for a valid measure of awareness of ADL ability. Because the main target population for the awareness measure is older adults (with stroke and/or dementia), we sought to validate the scale as representative of activities that older adults can carry out without difficulty.

A group of 61 dyads was recruited from a general population in Australia aged 60 or over randomly selected among those who regularly attended local clubs and associations. Exclusion criteria were (1) History of previous stroke or Transient Ischemic Attacks, (2) History of serious concussion or diagnosis of a neurological or psychiatric disease, (3) Evidence of reduced mobility. All interested participants received an information pack, containing the self and informant versions of the VATA-ADL, an information sheet and consent form, demographic questionnaire and a stamped-addressed envelope for the return of forms. Participants received a chocolate voucher as a token for their participation. They completed and retuned the VATA-ADL (described below).

The pairs consisted of older people (target participants; mean age= 72.17; SD= 8.86, range= 60-90; 40 women) and their informants (mean age= 58.43; SD= 17.5, range: 20-86; 34 women). All informants were partners, family-members or carers who interacted with the participants on a daily or weekly basis. Six older people provided incorrect responses to one or more of the check questions, and eleven informants proved unreliable for various reasons (did not complete the test, claimed not to know the older person well enough, provided incorrect responses to check questions). In three instances, the older person and the informant were from the same dyad, so fourteen dyads were excluded in total, leaving a final group of 47 dyads. The overall mean self-rating score of the remaining participants was 0.84 out of 54 (SD= 0.04), the mean of informants' rating evaluating the target participants was 1.51 out of 54 (SD= 0.05) and the mean discrepancy score between target participants and informants was 0.67 (SD= .05).

VATA-ADL – Study 2: Validation with post-acute stroke patients

This second study pertains to the validation of the VATA-ADL as a measure of awareness of possible impairments in conducting everyday tasks.

Participants

A total of 90 post-acute stroke patients (40 women) were recruited through clinics or stroke care facilities according to the following inclusion criteria: (i) diagnosis of first ischaemic or haemorrhagic stroke; (ii) no known psychiatric or neurological history prior to the brain damage; (iii) age between 18 and 90; (iv) availability of a caregiver, well-informed on the patient's everyday circumstances, typically a close family member, friend or professional caregiver who interacted daily with the patients. For 25 patients, two informants (one within the patient's personal entourage and one professional member of staff) completed the VATA-ADL. For these 25 patients we used the mean score of the pair of the informants for analyses. (v) time at testing more than one month since onset. Our choice of including patients from one month post-onset onwards was dictated by the usually accepted stroke staging labelling "acute" the first two weeks (e.g., Reheme et al., 2011; Vocat et al., 2010) together with the analysis of the cases reported as "chronic anosognosia" one can glean from the literature (see Table 1 in Cocchini et al., 2002) and as defined in Levine et al.'s (1991) study on the impact of time on anosognosia.

Six patients and two caregivers provided incorrect responses to one or more of the check questions. Data from 8 dyads were consequently excluded from analysis. Two further patients were excluded because the severity of their conditions prevented them from understanding the instructions, leaving a final sample of 80 dyads. The demographic data of the patients included in the study are reported in Table 2.

----- Insert Table 2 about here -----

General assessment

General cognitive abilities were assessed by the Mini Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975) in 68 patients. The MMSE average score was 24.14/30 (SD= 3.97; range= 14-30). Thirty patients (44.12%) scored below 24, indicating pathological performance. Functional skills on everyday activities were assessed by informant-completion of the Barthel Activities of Daily Living (Mahoney,

1965) for 72 patients, and of the NEADL (Nouri & Lincoln, 1987) for 13 patients (5 patients were assessed with both scales). The Barthel scores average was 79.33 (SD= 22.87; range= 5-100) and the NEADL scores average was 14.38 (SD= 7.03; range= 6-22). Both scales show that the patient group had substantial degree of dependence on average (Shah, Vanclay & Cooper, 1989), but the wide ranges indicate that the clinical sample was rather heterogeneous in functional ability.

VATA-ADL – assessment procedures

Patients were asked to rate their difficulty to perform the skills reported in each VATA-ADL item using the visual analogue scale (from 0=no problem to 3=problem). Each item (vignette, question, and rating scale) was displayed on the patient's ipsilesional side to compensate for any possible spatial attentional disorder (Cubelli, 2017). The analogue scale was explained orally by the experimenter as follows: "*Below each picture there is a rating scale. Please rank your ability by stating a number from 0 (no problem; you can perform this activity without any difficulty) to 3 (you have such serious difficulty with this activity that you would not be able to perform it). You can also provide the responses simply by pointing to the rating scale where appropriate. Let's try an example*" The experimenters repeated the instructions using the examples until they were sure that the participant fully grasped the task.

Caregivers completed the VATA-ADL independently, without witnessing the patients' responses, and in the same session whenever possible. Both patients and informants were asked to estimate possible difficulties for all the questions, even if a task was not directly recently experienced.

Results[3]

VATA-ADL as a measure of ADL

The mean informant-rated score for the VATA-ADL was 21.66 (SD= 14.52; range= 1-52) reiterating that the sample was heterogeneous in their functional ability. The informants' total scores on the VATA-ADL correlated significantly with the Barthel (Spearman's *rho* (70) = -.56; p < .001 and the NEADL (Spearman's *rho* (11)

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[3] Raw and processed data are available from https://osf.io/z9r2a/

= -.90; p < .001). These results indicate that the higher the VATA-ADL rating of difficulty the lower was the ability to perform everyday activities independently, suggesting that the VATA-ADL is a valid measure of ADL. The much higher correlation with NEADL was expected given that the VATA-ADL was loosely based on it (see VATA-ADL piloting).

Questionnaire structure

To investigate the unidimensionality of the VATA-ADL, a common factor analysis was conducted on the informants' scores for the 18 items. The items had good factorability; the Kaiser-Meyer-Olkin measure of sampling adequacy was .91, indicating that the sample size was sufficient for the analysis, and Bartlett's test of sphericity was highly significant, [χ^2 (153) = 1181.99, p < .001], demonstrating high levels of intercorrelation between the items. In addition, MSA values for all items were equal to or above .7.

The common factor analysis was conducted on all eighteen items using their Spearman correlation matrix (Watkins, 2018). For estimation, the principal axis method was used due to non-normal variable distributions (Watkins, 2018). Parallel analysis (Horn, 1965) as a recommended method to assess the adequate number of factors (Watkins, 2018) suggested two factors with an eigenvalue slightly above chance level for the second factor. Therefore, we compared both the one-factor and the two-factor solution. In the two-factor solution, factor 1 had an eigenvalue of 8.03 and explained 45% of the variance and factor 2 had an eigenvalue of 2.75 and explained another 15%; the two factors were highly correlated (*r* = .49). The unidimensional solution showed an eigenvalue of 9.29 for factor 1 with 52% variance explained. Apart from the high correlation of the two factors and the large difference in their eigenvalues, several cross-loadings occurred. Cross-loadings are critical, especially in our case where the two factors were also not meaningful from a theoretical perspective (Watkins, 2018).

Therefore, Table 3 presents the loadings and communalities for the one-factor solution. All items load substantially on the ADL-factor (factor 1). We also calculated Cronbach's *α* to assess unidimensionality. Although this measure should be treated with more caution than the factor analysis as Cronbach's *α* assumes normal data (Sheng & Sheng, 2012), we found further evidence for unidimensionality with

Cronbach's $\alpha = .95$ [.93; .96]. Taken together, this supports the unidimensionality of the VATA-ADL.

--- Insert Table 3 about there ---

VATA-ADL relationship with demographic, lesion side, and clinical variables

There were no significant differences in informants' VATA-ADL scores according to the gender of the patients [$t(78) = .43$; p = .67, d= 0.12; 95% CI's -5.16, 7.98], their educational level [$F(4,79) = .33$; p =.86; $\eta^2_{partial} = .02$,] or the hemisphere affected by the stroke [$t(74) = -1.89$; p= .062, d = 0.44; 95% CI's -13.02, .33].

The correlation of the informants' VATA-ADL scores with time since stroke (Spearman's *rho* (78) = -.04; p = .74) was not significant, nor was the correlation with patients' age (Spearman's *rho* (77) = .01; p = .95). A weak but significant correlation was found with the MMSE scores (Spearman's *rho* (66) = -.30; p = .01).

VATA-ADL as a measure of awareness

The informants' scores were taken as the measure of actual functional difficulty of the patients, where higher values indicated greater difficulties. The mean self-rated VATA-ADL score of the patients was 13.92 (SD= 12.32; range= 0-48). The mean score attributed by the informants was 21.66 (SD= 14.52; range= 1-52). The discrepancy scores (informant's minus patient's ratings) were considered to be measures of over-estimation (positive discrepancy) or under-estimation (negative discrepancy) of the patient's abilities in carrying out everyday activities.

Cut-off scores

In previous studies using the VATA format (Della Sala et al., 2009; Cocchini et al., 2010; Chapman et al., 2019), unawareness cut-offs were calculated by considering the range of discrepancies between the scores of pairs of informants evaluating the same patient. For 25 patients, two informants (one within the patient's personal entourage and one professional member of staff, including, neuropsychologists and clinical psychologists) completed the VATA-ADL. The discrepancy in scores between these two informants is used operationally to define the expected normal range of discrepancies between two people rating the same individual, whom they

know well. Where patient's self-ratings are significantly more discrepant than this 'normal' range, they are considered abnormal.

As shown in Figure 2a, the correlation between informant ratings was very high (Spearman's *rho* (23) = .98; p <.001). Since the cut-off calculation relies on discrepancies between informants, it is crucial to avoid extreme cases (i.e., either with no/very mild disabilities or too severe disabilities) to ensure some discretion of interpretation. Considering extreme cases in this analysis would result in too conservative cut-off values leading to an inflation of false alarms during the diagnosis. Exploring informants' ratings, we have identified seven patients (unfilled circles in Figure 2a) showing very minimal, if any, disability, having a disability score between 2 and 5 out of 54 (< 9%). No patients on the opposite extreme (i.e., too severe with disability scores closer to 54) were identified in this sample. Therefore, for the calculation of cut-offs, only seven pairs of informants were excluded as the patients they rated showed minimal, if any, disability. Cut-offs were calculated from the remaining 18 pairs (filled circles).

----- Insert Figure 2 about here -----

We first calculated the discrepancy between informant ratings as absolute (unsigned) values because the direction of discrepancy between them was considered arbitrary. We then estimated the expected variance of signed discrepancies, by a resampling method, repeated 1000 times. In each iteration, we signed half of the discrepancies negatively at random and calculated and stored the variance of the resultant distribution. The average variance across 1000 iterations was then calculated, and the square root (2.27) taken as the estimate of the standard deviation of signed discrepancies around an assumed mean of zero. Upper and lower cut-offs were calculated using Crawford's and Howell's (1998) modified t-test formula, assuming a mean discrepancy of zero, with a standard deviation of 2.27, for a control sample size of 18, and applying a two-tailed significance criterion at p = .01. Following this method, symmetrical two-tailed cut-offs for Underestimators and Overestimators of their own abilities were set at discrepancy scores of -6.8 and + 6.8, respectively. Discrepancy scores between the two cut-offs indicate normal performance (Aware).

Analysis of patient self-estimation

A scattergram of the relation between patient and informant ratings is shown in Figure 2b. The correlation between these ratings was moderate (Spearman's *rho* (78) = .51, p < .001), and much lower than that between pairs of informants (Figure 2a). This implies a considerable degree of uncertainty in the patients' self-ratings. The mean discrepancy between patient- and informant-rated scores was 7.74 (SD= 13.0; range= -19 to 36.50; 95% CI's 4.85-10.63). This differed significantly from zero according to a one-sample t-test (t(79) = 5.32, p < 0.001, d = 0.60), so the overall tendency was for patients to overestimate their own functional abilities.

Applying the cut-offs, 60 per cent of the patients overall (48/80) mis-estimated their abilities, with Overestimators (n = 39) around four times more numerous than Underestimators (n = 9). A Welch's t-test to compare the absolute (unsigned) magnitude of mis-estimation between Overestimators (M= 18.64; SD= 8.20) and Underestimators (M= 13.11; SD= 4.65) found that overestimation was also more severe on average than underestimation [t(21.30) = 2.72; p = .01, d = 0.72; 95% CI's -9.75, -1.31].

A total of 14 Overestimators had left brain damage (45%), whereas 24 had right-brain damage (53%) (lesion data were missing for one patient); 3 and 5 Underestimators had left- and right-brain damage, respectively (lesion data were missing for one patient). The level of general cognitive ability, as measured by the MMSE, was similar between Overestimators (M= 23.26; SD= 3.54) and Underestimators (M= 22.29; SD= 3.73), but generally lower than that in the Aware group (25.55; SD= 4.13). Overestimators had a greater overall degree of impairment in functional ADL, as estimated by the informant's ratings [t(46)= 3.65; p = .001, d = 1.35; 95% CI's -23.57, -6.82].

Item analysis

A subsequent analysis was run to address which VATA-ADL items were best predictors of unawareness (i.e., had the most positive discrepancy score for Overestimators and most negative score for Underestimators). Following a similar procedure as in Della Sala et al. (2009), we calculated for both groups the average discrepancy for the 18 items (see Table 4). Underestimators tended to show the greatest discrepancy with informants on questions such as 'Traveling on public

transport' and 'Crossing the road' where they underestimated their abilities. On the contrary, Overestimators tended to show the greatest discrepancy with the informants on questions such as 'Crossing the road', 'Taking medication', 'Shopping' and 'Traveling on public transport' where they overestimated their abilities.

--- Insert Table 4 about there ---

Discussion

Awareness of one's own problems in carrying out daily activity tasks is rarely assessed, yet it may be very relevant for the day-to-day management of people with brain damage. The Visual-Analogue Test for Anosognosia for Activities of Daily Living (VATA-ADL) was devised to meet the need of assessing people's performance on daily activities as well as their awareness of such performance. The test allowed us to assess self-estimation of ADL in patients who would usually be excluded due to their incapacity to understand verbal questions (for discussion see Cocchini et al., 2012).

VATA-ADL proved a reliable measure of long-term functional disabilities (when rated by an informant) and it measures awareness of disability (when comparing self-ratings to informants' ratings). The scale has good internal consistency as well as predictive and factorial validity and appears to measure a coherent construct. It also correlates significantly with traditional measures of ADL and iADL, demonstrating convergent validity.

The VATA-ADL items were selected to cover three main everyday domains related to self-care, and activities inside and outside the house. A factor analysis and the analysis of internal consistency support that all three domains are unified by the ADL-factor. Cronbach's α showed a large value of $\alpha = .95$ and all items loaded substantially on one factor. The ADL-factor also explained a large amount of variance in ADL awareness (52%). Therefore, the VATA-ADL appears to measure a coherent construct.

Lack of awareness of ongoing problems in daily living has received little attention in the stroke literature, perhaps because anosognosia is typically considered a phenomenon characterising the acute stages after a stroke, which later resolves (Jehkonen, Ahonen, Dastidar, Laippala & Vilkki, 2000; Starkstein, Jorge & Robinson,

2010). However, there have been sufficient cases of post-acute anosognosia reported in the literature to suggest that anosognosia is not an exclusively acute stage phenomenon (Cocchini et al., 2002; Orfei et al. 2007; D'Imperio et al., 2017). It is therefore important to assess long-term difficulties in performing everyday tasks and awareness of such limitations, in the pot-acute stages following a stroke, once the patients return to live at home.

About half of the post-acute stroke patients entering this study underestimated their difficulties. This frequency is not unusual, given the very wide range of estimates for the frequency of anosognosia for other impairments following brain damage, which ranges from 7% to 77% (Orfei et al., 2007; Jehkonen, Laihosalo & Kettunen, 2006; see also Tables 1 and 4 in Nurmi & Jehkonen, 2014). This variability may be due to different diagnostic criteria, different instruments used, the recruitment of patients at different intervals post-onset, or to the fact that patients assessed in the post-acute phases of their disease may have learned the "right" answers to some common questions used to assess anosognosia (Cocchini et al., 2009, 2012; Nurmi & Jehkonen, 2014). The finding that such a large number of patients underestimate their difficulties indicates that self-reports should be used with caution, as if patients lack awareness for their own true level of ability, then the outcome would be biased. This result is in apparent contrast with the accrued wisdom that long-term anosognosia is rare (e.g., Jehkonen et al., 2000; Vocat, Staub, Stroppini & Vuilleumier, 2010). Indeed, post-acute anosognosia is not rare when some assessment limitations are by-passed and more sensitive tools are used (Cocchini et al., 2002; Orfei et al., 2007). This finding is important as unawareness of one's own disability to undertake daily activities could have serious implications for the day-to-day safety of the patients (Hartman-Maeir, Soroker, & Katz, 2001; D'Imperio et al., 2017), for the use of conscious forms of compensation (Jenkinson, Edelstyn, Drakeford & Ellis, 2009; Richardson, McKay & Ponsford, 2015), and could cause stress to their caregivers, who may struggle to manage these behaviours (Heilman & Harciarek, 2010; Prigatano, 2005). Informal reports provided by caregivers during the debriefing suggested that, at times, unawareness led to potentially dangerous behaviours, for example spilling water all over the floor or inadequate fire safety when cooking. This could be particularly difficult to cope with once the patient has returned home, away from professional support.

One of the central questions in post-acute anosognosia research is whether long-term unawareness depends upon the presence of persistent deficits in cognitive ability (Levine, 1990; Levine, Calvanio & Rinn, 1991; Cocchini et al., 2002; Davies et al., 2005). In addition to any effects on the ability to carry out daily activities, different cognitive impairments may have differential relationships with awareness. In the current study, none of the demographic variables differed significantly across the three VATA-ADL awareness categories of Underestimators and Overestimators. Patients with misestimation did tend to have lower MMSE scores than patients classified as Aware. Even so, the MMSE provides a very coarse cognitive assessment only, and does not differentiate which aspects of cognitive functioning are compromised in stroke patients (Pendlebury, Mariz, Bull, Mehta & Rothwell, 2012). Future research with the VATA-ADL should incorporate a comprehensive set of tests, including specific assessments of attention, memory praxis and executive functions, to investigate which deficits are more associated with actual ADL impairment and which with misestimation of abilities.

Contrary to the historical (Babinski, 1923) and conventional tenet (Gainotti, 2018) stating that anosognosia is a right hemisphere symptom (see Baier et al., 2014; Fowler, Della Sala, Hart & McIntosh, 2017) a sizeable proportion of LBD patients in the current study presented with unawareness of their problems in carrying out daily activities, making it unlikely that anosognosia for ADL is an exclusively right-hemisphere problem. In general, when patients with language problems are not excluded from assessment, the difference of anosognosia frequency across the two hemispheres decreases, as it minimises the bias towards assessing severe RBD but not severe LBD patients (Della Sala et al., 2009; Cocchini and Della Sala, 2010). Similarly, the tendency to overstate own difficulties was not linked to lesions of a particular hemisphere.

The current study did not incorporate any measure of anosognosia for specific problems, for example motor impairments, amnesia, or aphasia. Therefore, it cannot be determined how encompassing the unawareness of those patients who overestimated their ADL ability was. It would therefore be interesting if future research incorporated other, preferably validated, measures of anosognosia for specific deficits, to address whether some VATA-ADL Overestimators are aware of

more specific deficits, and whether any specific type of anosognosia is more likely to predict unawareness of ADL problems.

Misestimation was more severe in patients with more disability (as rated by informants) than in those with milder functional problems, and this was particularly true for Overestimators (Figure 2b). However, this pattern is relatively unsurprising, given that the informant rating itself contributes to the misestimation score. In a strict numerical sense, a patient rated with high disability has more possibility to overestimate themselves, and vice-versa for a patient with low disability. It is therefore arguable that we can only securely conclude that our patients were generally poor at self-estimation, considering that the specific pattern of misestimation (Under- or Over-) may be shaped by regression artefacts. Moreover, if a patient who was unsure of their real level of ability were to optimistically rate themselves as relatively unimpaired, then this would also lead to a general trend towards overestimation at a group level. It remains to be determined, then, whether there are real differences in cognitive profile between Overestimators and Underestimators. Fowler et al. (2018) reported that Overestimation (anosognosia) was disproportionately likely amongst RBD patients, while underestimation was a feature of LBD patients, but the same pattern in relation to side of lesion was not apparent in the present study.

The prevailing pattern towards overestimating own abilities observed in the current study is consistent with the classical pattern of anosognosia (lack of awareness of own disability), although underestimation did also occur. The phenomenon has not been widely reported in the literature of anosognosia (see Fowler et al., 2018 for stroke, and Edmonds et al., 2018 for non-progressive mild cognitive impairment and healthy ageing). Here we report it for ADL, indicating that some stroke patients underate their performance in daily activities. This could be clinically relevant given the previously observed association between mood and self-estimation, which suggests a tendency among people with brain damage with lower moods to underestimate their abilities (Besharati et al., 2014; Fowler et al., 2018; Langer & Levine, 2014). It would be relevant in future research to investigate the relationship between overestimation of one's own disabilities and mood in selected groups of people with brain damage.

Moreover, in this study we have assessed a group of stroke patients. However, ADL and iADL scales traditionally have been developed to assess competence in everyday tasks by frail older people or people affected by early stages of dementia (De

Vriendt et al., 2012; Lawton & Brody, 1969; Nygård, 2003). Future studies should check the compliance, the inclusivity, the reliability, and the outcome of the newly devised VATA-ADL against more traditional scales assessing frail older people or people affected by pathological ageing.

A further point that future research should consider is that of the informants' evaluation. Although daily abilities might ideally be operationalised by performance observations at home, giving questionnaires is far more feasible. Some studies have shown that caregivers' ratings are adequate objective measures of the patient's deficit (Fleming, Strong & Ashton, 1996). However, caregivers' ratings may also be affected by personal factors (Prigatano, Borgaro, Baker, Wethe, 2005; Godfrey et al., 2003) and when compared with performance-based measures such ratings displayed poor face validity (Fieo, Austin, Starr, Deary, 2011: Guralnick & Simonsick, 1993). We labelled this particular case of informant bias (MacAulay, 2012) ''Caring for patients effect'' (Smith et al., 2000; for a discussion see Persson et al., 2015), which is not simply an effect of reporting on behalf of someone else and raises some important methodological issues. Informants, and carers in particular, may demonstrate unintentional biases in their vetting of the patient's performance (McLoughlin et al., 1996), either by comparing their own performance with that of the patients they care for, hence underestimating the patient's real performance (see Rabbitt, 1984), or by mechanisms of disease denial which lead them to overestimate the patient's real capacity (Loewenstein et al., 2001). Therefore, the VATA-ADL, even if ultimately developed into a fully-validated and reliable tool, could only ever be used as an aid to determine the individuals' awareness of their current ability to carry out ADLs, avoiding its use as a final arbiter or 'capacimeter' (Kapp & Mossman, 1996). In line with formal clinical guidelines (ABA/APA, 2008 ; APA, 2021), any such tool should be used alongside other crucial clinical methods involving interviews to clarify the

patients' background and to guide any attempt to increase the patient's understanding of questions about everyday functioning and insight into their own everyday functions.

Future studies should consider comparing the patients' own ratings also with their actual performance (see Berti et al., 1996; Marcel, Tegnér & Nimmo-Smith, 2004) to check that VATA-ADL can predict actual performance in daily activities (for discussion see Burton et al., 2009 and Gold 2012).

In conclusion, we have presented a new tool to assess awareness of ADL/iADL based on vignettes and visual-analogue scales. The test proved reliable and appropriate to increase compliance and reduce exclusion due to the limited verbal component. Using this instrument, we showed that stroke patients in general seem to have a poor appreciation of their functional abilities (by comparison to informant assessments). The tendency is towards overestimation of own abilities (anosognosia), which would be consistent with gravitating towards a default assumption that one is functionally able, rather than disabled. However, some patients showed underestimation of their abilities which could equally be argued to represent a lack of insight. Whether there are meaningful cognitive distinctions between patients who misestimate their performance in different direction is unclear, and is a question deserving further attention. Finally, the VATA-ADL should be considered a nascent tool for research on self-monitoring of daily abilities. Further development and validation would be required before considering any practical or clinical applications with confidence. For reliable clinical deployment, the VATA-ADL would require additional support including evidence that the items composing the scale reflect an adequate sample of relevant ADL and iADL.

Disclosure Statement

No potential conflict of interest is reported by the authors.

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Table 1. List of VATA-ADL items.

Practice item:
    Washing dishes

Target- Items
Self-care activities:
2. Feeding yourself
3. Washing your face
8. Taking a bath or shower
14. Getting dressed and undressed
18. Combing your hair
21. Taking your medication
Activities inside the house:
6. Writing letters
10. Making hot drinks
12. Using the telephone
15. Making a hot snack
20. Watering plants
22. Reading the newspaper
Activities outside of the house:
1. Getting in and out of the car
5. Managing money
7. Crossing the road
11. Travelling on public transport
16. Doing the shopping
17. Going out socially

Control items:
'Achievable' – Expected rating 0-1
    4. Hearing a loudspeaker
    13. Recognizing yourself
'Not achievable' – Expected rating 2-3
    9. Pulling a lorry
    19. Trapeze

Table 2. Demographic and clinical data of the people with stroke participating in Study 2 (n=80).

Gender	46 (57.5%) men 34 (42.5%) women
Age[1]	Mean: 60.44 SD:14.70 Range: 20-87
Education	Mean years: 11.36 (SD:4.17; range: 5-19) Primary school: 5 (6.25%) Secondary school: 30 (37.5%) College: 20 (25%) University undergraduate: 16 (20%) University postgraduate: 9 (11.25%)
Time since stroke	Mean months: 26.65 SD:41.95 Range:1-267
Side of lesion[2]	31 (38.75%) left brain damage 45 (56.2%) right brain damage 2 (2.5%) bilateral

[1] For one patient, age was not given in the files.
[2] Lesion data were missing for two patients (2.5%)

Table 3. Standardized factor loading matrix (pattern matrix) for VATA-ADL items.

Would you have difficulties?	Factor 1 – ADL	Communality
Question no.		
1. Getting in/out of the car	0,79	0,63
2. Feeding him/herself	0,78	0,61
3. Washing face	0,65	0,42
5. Managing money	0,71	0,51
6. Writing letters	0,52	0,27
7. Crossing the road	0,86	0,74
8. Taking bath or shower	0,88	0,77
10. Making hot drinks	0,82	0,67
11. Traveling on public transport	0,79	0,63
12. Using the telephone	0,53	0,28
14. Getting dressed and undressed	0,82	0,67
15. Making a hot snack	0,89	0,79
16. Doing the shopping	0,73	0,54
17. Going out socially	0,49	0,24
18. Combing hair	0,66	0,43
20. Watering plants	0,81	0,66
21. Taking medication	0,57	0,33
22. Reading the newspaper	0,31	0,1

Note. Items 4, 9, 13 and 19 were control items and they were not included in this analysis

Table 4. Discrepancy item analysis for Underestimators and Overestimators of their own abilities.

UNDERESTIMATORS			OVERESTIMATORS		
	Mean discrepancy	SD		Mean discrepancy	SD
Traveling on public transport	-1.44	1.13	**Crossing the Road**	1.54	0.83
Crossing the Road	-1.22	0.97	**Taking medication**	1.46	0.85
Taking bath or shower	-1.11	0.78	**Doing the shopping**	1.45	1.11
Getting dressed and undressed	-1.00	0.71	**Traveling on public transport**	1.42	1.09
Making a hot snack	-1.00	0.71	Going out socially	1.33	1.02
Doing the shopping	-1.00	0.71	Managing money	1.24	0.95
Getting in/out of the car	-0.89	1.45	Writing Letters	1.21	0.82
Making hot drinks	-0.89	0.78	Watering plants	1.13	1.04
Using the telephone	-0.78	1.30	Making a hot snack	1.09	1.15
Going out socially	-0.78	0.67	Reading the newspaper	1.09	0.92
Writing Letters	-0.67	1.41	Taking bath or shower	1.06	1.01
Combing your hair	-0.67	0.87	Making hot drinks	0.99	1.00
Washing face	-0.56	0.73	Getting dressed and undressed	0.92	0.91
Feeding yourself	-0.44	0.73	Using the telephone	0.69	0.74
Reading the newspaper	-0.44	1.59	Getting in/out of the car	0.68	1.12
Watering plants	-0.28	0.83	Washing face	0.65	1.01
Managing money	0.00	0.71	Feeding yourself	0.37	0.79
Taking medication	0.06	0.95	Combing your hair	0.31	0.61
Mean	-0.73		Mean	1.04	
SD	0.40		SD	0.37	

Items in bold indicate higher discrepancies (over 1 SD from the group mean) for Underestimators and Overestimators.

Figure 1. Examples of VATA-ADL assessment (A & B) and check (C) questions with visual analogue scale (D).

A

Do/Would you have difficulty making yourself hot drinks?

B

Do/Would you have difficulty travelling on public transport?
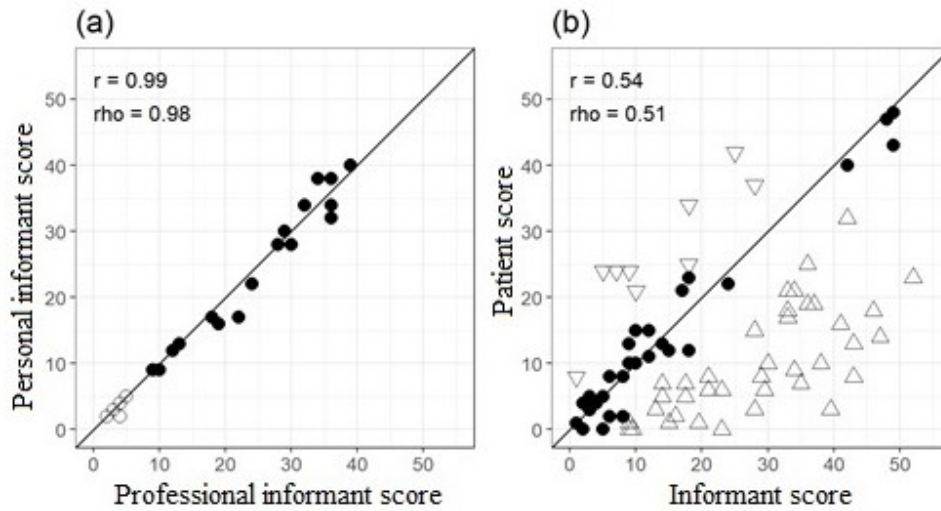
C

Do/Would you have difficulty pulling a lorry?

D

No Problem   Problem
0 --------- 1 --------- 2 --------- 3

Figure 2. (a) Scattergram showing the relation between professional and personal informant scores. **(b)** Scattergram showing the relation between informant and patient scores.

The pairs represented by the filled circles in the graph (a) were used for the calculation of discrepancy cut-offs.

The unfilled triangles in (b) represent patients performing outside of cut-offs. Downward pointing triangles represent patients classed as Underestimators of their abilities; upward pointing triangles represent patients classed as Overestimators, and filled circles represent patients classed as 'Aware'.