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Awareness of Disease in Dementia: Factor Structure of the Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia

Marcia C.N. Dourado[a,*], Daniel C. Mograbi[b,c], Raquel L. Santos[a], Maria Fernanda B. Sousa[a], Marcela L. Nogueira[a], Tatiana Belfort[a], Jesus Landeira-Fernandez[b] and Jerson Laks[a]
[a]*Center for Alzheimer's Disease, Institute of Psychiatry, Universidade Federal do Rio de Janeiro, Rio de Janeiro, Brazil*
[b]*Department of Psychology, Pontifícia Universidade Católica do Rio de Janeiro, Rio de Janeiro, Brazil*
[c]*Department of Psychology, Institute of Psychiatry, King's College London, London, UK*

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Abstract. Despite the growing understanding of the conceptual complexity of awareness, there currently exists no instrument for assessing different domains of awareness in dementia. In the current study, the psychometric properties of a multidimensional awareness scale, the Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia (ASPIDD), are explored in a sample of 201 people with dementia and their family caregivers. Cronbach's alpha was high ($\alpha = 0.87$), indicating excellent internal consistency. The mean of corrected item-total correlation coefficients was moderate. ASPIDD presented a four-factor solution with a well-defined structure: awareness of activities of daily living, cognitive functioning and health condition, emotional state, and social functioning and relationships. Functional disability was positively correlated with total ASPIDD, unawareness of activities of daily living, cognitive functioning, and with emotional state. Caregiver burden was correlated with total ASPIDD scores and unawareness of cognitive functioning. The results suggest that ASPIDD is indeed a multidimensional scale, providing a reliable measure of awareness of disease in dementia. Further studies should explore the risk factors associated with different dimensions of awareness in dementia.

Keywords: Alzheimer's disease, anosognosia, awareness of disease, dementia, factor analysis

INTRODUCTION

Awareness of disease can be defined as the ability to acknowledge difficulties and cognitive impairments caused by an illness, being often reduced in people with dementia [1, 2]. Awareness can be expressed at different levels, including ability to monitor immediate performance, to make evaluative judgments about functioning in a given domain, and to reflect on the nature and impact of a diagnosis or health condition [3]. Awareness may be progressively impaired in dementia, in accordance with the decline that occurs along the natural history of the disease, and is associated with the loss of specific abilities, such as memory, executive functions, and attention [1, 4, 5]. Unawareness of specific deficits may have different causes, such as dysfunction of mechanisms related to self-monitoring, episodic memory deficit, frontal dysfunction, disconnection of damaged brain areas from central monitoring systems, or psychological defense mechanism [6, 7].

*Correspondence to: Marcia C.N. Dourado, Rua Jardim Botânico, 700/513, 22461-000 Rio de Janeiro, Brazil. Tel./Fax: +55 21 25473863; E-mail: marciacndourado@gmail.com.

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The Cognitive Awareness Model (CAM) [8–10] has been formulated to explain the heterogeneity of unawareness in dementia and postulates the existence of different causes for awareness. For example, unawareness can result from: (a) executive dysfunction, with impaired ability to detect a discrepancy between current deficits/performance and previously formed self-knowledge (executive unawareness); or, from (b) memory dysfunction, which prevents updating of self knowledge matching the development of deficits and thus results in outdated self-knowledge (mnemonic unawareness) [11]. In addition, direct impairments in metacognition may also be present due to disconnection between brain areas. It seems likely that unawareness of disease is produced by a complex interplay of factors, which vary between individuals [12].

Leicht et al. [13] suggested that one issue in this area is the absence of a single established method for assessing awareness of disease. Instead, three approaches have been typically used [14]. One is to let an experienced clinician rate the patient's level of awareness, based on interviews with the patient and a caregiver [15, 16]. A second approach involves exploring discrepancies from parallel questionnaires for people with dementia (PwD) and caregivers which address potential impairment; subtracting patient's ratings from the caregiver's ratings yields a discrepancy score that reflects the degree of unawareness [1, 17]. A disadvantage is that caregiver ratings can be biased by factors such as the caregiver-patient relationship or caregiver distress [18]. However, at the same time, caregiver ratings have been shown to be largely accurate [19, 20]. Caregivers are also the best source of information regarding deficits in activities of daily living. The third method is based on the comparison of a patient's cognitive performance in standardized neuropsychological tests and his or her assessment of this performance [8, 21]. Discrepancies between performance and self-assessment are interpreted as indicators of unawareness. Nevertheless, as self-assessment of test performance is prone to errors even in healthy subjects [22], this method requires a healthy control group to detect errors exceeding the normal range. In addition, many activities of daily living cannot be assessed properly in a neuropsychological test.

A second issue is whether awareness of disease in AD affects specific areas of function more than others. Awareness itself is demonstrated in relation to a given focus or object through the involvement of cognitive processes of varying degrees of complexity. Possible objects of awareness include internal states, external stimuli, symptoms, or changes in functioning [23–25]. Studies suggest that different domains of awareness may elicit independent phenomena, such as awareness of cognitive deficits, functional impairment, or behavioral disturbances [6, 23, 26].

Unawareness of disease cannot be considered as a unitary entity [9, 27, 28]. It is possible that awareness has varying impairment levels and correlates according to its object. Vasterling et al. [29] reported that unawareness was most prominent in ratings of memory and self care, less prominent in ratings of anxiety and irritability, and absent in ratings of depression and health status. Another study showed that unawareness is manifested as poor recognition of deficits mainly in instrumental and basic activities of daily living (ADL), depressive changes, and behavioral disinhibition [23]. Green et al. [30] found unawareness for recent memory and ADL, as opposed to attention and long-term memory. Other studies that examined cognition only report selective unawareness for specific cognitive functions [17]. Memory is the cognitive domain most often studied in relation to unawareness, but beyond memory, virtually no two studies have investigated the same set of domains.

There is considerable discrepancy in the evidence for specificity of unawareness in AD, with some studies indicating domain-specific deficits [31], while others find impairments across cognitive abilities or tasks [32]. While a number of studies on dementia have examined aspects related to unawareness of cognitive and behavioral deficits, less is known about the impairment in awareness of social and emotional deficits. Nelis et al. [33] found no significant relationship between awareness of social-emotional functioning and self-reported quality of life (QoL). Awareness of emotional states may be distinct from awareness of cognitive function [33]. While PwD may eventually lack direct awareness of their ADL function and performance, they may nonetheless retain awareness of the feelings these tasks elicit [29].

Despite the growing understanding of the conceptual complexity of awareness, there currently exists no instrument for assessing different domains of awareness in dementia [8, 24, 34]. As a broader alternative, we developed the Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia (ASPIDD) [1], a multidimensional scale based both on PwD and informant report. The ASPIDD was designed to evaluate awareness of disease in PwD through the scoring of discrepant responses across domains that include awareness of cognitive deficits, family and social relationships, and instrumental and basic ADL.

Despite its conceptual development as a multidimensional tool, it is necessary to determine how many dimensions are actually measured by this instrument. Likewise, the factor structure of the scale has not been explored yet. The aim of the present study was, therefore, to investigate the psychometric properties of the Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia (ASPIDD).

MATERIAL AND METHODS

Participants

A consecutive series of 201 PwD and their family caregivers were recruited from an AD outpatient unit and included in the study. The clinical diagnosis of AD was made by a psychiatrist through the application of cognitive screening tests and a complete blood cell count, platelet count, glycemia, triglycerides, total cholesterol and fractions, alkaline phosphatase, glutamic oxaloacetic transaminase and glutamic pyruvic transaminase, bilirubins, urea, creatinine, total proteins, calcium, free T4 levels, TSH, VDRL, dosage of B12, and folates. Cranial CT scan or MRI scan with or without spectroscopy were also applied.

The participants were diagnosed with possible or probable AD according to DSM-IV-TR [35] and NINCDS-ADRDA criteria [36]. People with mild to moderate AD according to the Clinical Dementia Rating (CDR) [37] and scores ranging from 13 to 27 in the Mini-Mental State Examination (MMSE) [38] were included in the study. Exclusion criteria were uncontrolled clinical problems, such as hypertension and diabetes, and presence of psychiatric or neurological disorders such as aphasia, head trauma, alcohol abuse, and epilepsy, as defined by the DSM IV-TR criteria [35].

The primary family caregiver was defined as the individual who was responsible for most of the care of the PwD. Each caregiver resided in the same house as the PwD, and was able to provide detailed information on the person's life history, cognitive functioning, and ADL. All caregivers had previously been informed of their relatives' diagnosis by a psychiatrist.

Each PwD-caregiver dyad was interviewed together. PwD completed ratings regarding awareness of disease, QoL, and cognition. Caregivers completed all demographic measurements as well as informant ratings of ADL, QoL, depression, dementia severity, and burden of care, as shown below. For the interview with the PwD, the research assistant read questions with accompanying large-type visual displays of the answer choices. In the event a PwD expressed confusion over the question or its answer choices, the research assistant made efforts to clarify instructions. Assessments were carried out in the same order for all participants.

Table 1
Background variables divided by group

Variable	PwD ($n = 201$) Mean (SD)/Range	Caregivers ($n = 201$) Mean (SD)/Range
Age	75.6 (7.3)/58–93	58.6 (14.8)/18–93
Gender*	130/71	141/60
Years of education	8.3 (3.5)/3–15	10.7 (3.3)/0–15
MMSE	20.3 (3.8)/12–27	–
Years since onset	4.4 (2.3)/1–14	–
FAQ	16.4 (8.5)/0–30	–
QoL-AD	34.1 (6.3)/15–52	30.3 (7.4)/12–48
Zarti		27.1 (14.6)/0–70
CORNELL	4.4 (3.3)/0–19	–
ASPIDD total score	7.5 (5.7)/0–25	–

*# female/male. MMSE, Mini-Mental State Examination, FAQ, Pfeffer Functional Activities Questionnaire; QoL, Quality of Life in Alzheimer's Disease scale; Zarit, Zarit Burden Interview; CORNELL, Cornell Scale for Depression; ASPIDD, Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia.

Socio-demographic and clinical characteristics of the sample are described in Table 1.

Measures

Awareness of disease

The ASPIDD [1] is a 30-question scale based on PwD-caregiver reports and was designed to evaluate awareness of disease in PwD through the scoring of discrepant responses across domains that include awareness of cognitive deficits, social relationships, family relationships, instrumental and basic ADL. The caregiver answers the same questions as the PwD and is not allowed to discuss the questions with the PwD or to assist the PwD in any way. The score was based on the degree of discrepancy between the PwD and caregiver dyad responses, with one point being scored for each discrepant response. The ratings of awareness range from preserved (0–4), mildly impaired (5–11), moderately impaired (12–17), to absent (over 18).

Quality of life

The Quality of Life in Alzheimer's Disease (QoL-AD) [39, 40] is a 13-item self-report and caregiver measure of quality of life that was developed specifically for the assessment of quality of life in dementia. The QoL-AD includes the following domains: physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self, and life as a whole. The 13 items are rated as poor (1), fair (2), good

(3), or excellent (4) and total scores range from 13 to 52. Ratings were collected with PwD and caregivers, and were analyzed separately.

Cognitive status

Cognitive level was measured with the MMSE, which includes tests on orientation, registration, short-term memory, language use, comprehension, and basic motor skills. The scores range from 0 to 30, with lower scores indicating impaired cognition [38, 41].

Dementia severity

Severity of dementia was measured with the CDR. Dementia severity is categorized from zero (no dementia) to six (severe dementia) according to the degree of cognitive, behavioral, and ADL impairment. In the current study, the full CDR protocol was used [37, 42].

Mood

The Cornell Scale for Depression in Dementia (CORNELL) assesses mood symptoms, physical signs, circadian functions, and behavioral symptoms related to depression in dementia. Scores above 7 indicate the presence of mild, moderate, or severe depression [43, 44].

Activities of daily living

The Pfeffer Functional Activities Questionnaire (FAQ) is a caregiver-reported inventory that evaluates activities of daily living capacity. The ratings for each item range from normal (0) to dependent (3), with a total score of 30, and higher scores indicate worse functional status [45].

Caregiver burden

Burden was measured with the Zarit Burden Interview (ZBI), which contains 22 items. The caregiver assesses the impact of the PwD illness on his/her life by indicating how often he/she experiences a particular feeling: never (0), rarely (1), sometimes (2), quite frequently (3), or nearly always (4). Scores range from 0 to 88, with higher scores indicating higher level of burden [46, 47].

All assessments were conducted by trained research assistants. This study was approved by the Ethics Committee of the Institute of Psychiatry at the Federal University of Rio de Janeiro (UFRJ) CAAE0028.0. 249.000-09. Informed consent was obtained directly from PwD and their caregivers prior to the first interview.

Data analysis

The Kaiser-Meyer-Olkin (KMO) measure was calculated to evaluate sampling adequacy in order to carry out an exploratory factor analysis. It has been suggested that KMO values should be equal to or above 0.60 in order to perform and interpret satisfactorily a factor analysis solution [48]. We used maximum likelihood (ML) extraction instead of principal components analysis because the latter procedure does not discriminate shared from unique variance, inflating variance estimates [49]. ML has been recommended as an extraction method even in cases when data is not normally distributed [50, 51]. Factor rotation was performed through an oblique method (promax, $\delta = 0$), because of potential conceptual correlation among the factors. Examination of scree-plot and parallel analysis [52] were employed to determine the number of factors, with the latter procedure being performed through a SPSS syntax developed by O'Connor [53]. Following Floyd and Widaman [54], factor loadings above 0.30 were considered relevant.

In order to test whether the ASPIDD has a hierarchical factor structure, a second-order factor analysis was conducted on the four oblique factors in the same manner as previously described. Based on the second-order factor analysis, the Schmid-Leiman orthogonalization procedure [55] was employed to investigate item loading in the higher- and lower-order factors. This procedure was carried out using SPSS syntax codes developed by Wolff and Preising [56]. Factor loadings equal to or greater than 0.25 are generally considered satisfactory.

Cronbach's alpha was calculated for the full scale and the extracted factors, for the full sample and split by dementia severity (mild and moderate). Finally, Pearson's correlations were calculated to establish the relationship between higher- and lower-order ASPIDD factors, as well as the association with clinical variables such as caregiver burden, depression, and quality of life.

RESULTS

The mean total ASPIDD score was 7.5 (SD = 5.7), ranging from 0 to 25. Cronbach's alpha was high ($\alpha = 0.87$), indicating good to excellent internal consistency of the scale [57]; internal consistency remained high dividing the sample according to dementia severity (mild severity: $\alpha = 0.83$; moderate severity: $\alpha = 0.87$). The mean of corrected item-total correlation coefficients was moderate ($r = 0.39$), ranging from

Table 2
Factor loadings of the 25 ASPIDD scale items obtained with maximum likelihood analysis and oblimin rotation

		ASPIDD Factors			
Item #	Item	I	II	III	IV
20	Has your routine changed lately?	**0.82**	−0.23	0.05	−0.03
26	Do you take care of your personal hygiene on your own?	**0.69**	−0.16	0.02	0.12
21	Do you think that your routine has changed because of health problems?	**0.65**	−0.16	0.12	0.02
22	Do you need help to perform your tasks?	**0.60**	0.16	−0.06	0.06
28	Do you remember schedules and family events?	**0.56**	0.14	−0.02	−0.08
27	Can you pay attention to and understand TV/radio shows, journals or magazines?	**0.47**	0.29	−0.08	−0.06
15	Currently, has your desire to be with the people changed because of a health problem?	**0.45**	0.02	0.20	−0.09
11	Do you think you have a health problem?	0.29	0.15	0.04	0.14
05	Do you have difficulties in recognizing persons or things?	−0.23	**0.66**	0.01	0.01
04	Have you already got lost in places you know?	−0.07	**0.56**	−0.01	0.02
29	Do you usually go out alone?	0.21	**0.52**	−0.11	0.06
01	Do you have memory problems?	0.05	**0.48**	0.21	0.03
24	Do you go shopping alone?	0.21	**0.44**	−0.22	0.03
13	Did you enjoy having visits at home?	−0.14	**0.43**	0.07	−0.06
03	Has anybody already told you what you have?	0.05	**0.43**	0.08	−0.02
02	Do you think you have a disease?	0.05	**0.39**	0.11	0.05
23	Do you handle money?	**0.30**	**0.36**	−0.06	−0.01
25	Are you more satisfied than before because of health problems?	−0.16	**0.34**	0.23	0.09
10	Do you take care of you home on your own	0.13	**0.33**	0.01	−0.03
30	Can you drive?	−0.01	0.26	0.16	−0.03
09	Are you angrier than before because of health problems?	−0.03	−0.01	**0.82**	0.12
08	Are you more anxious than before because of health problems?	−0.03	0.04	**0.71**	−0.03
07	Are you happier than before because of health problems?	0.24	0.07	**0.50**	−0.08
06	Are you sadder than before because of health problems?	0.18	0.04	**0.46**	−0.11
14	Did you have much contact with your friends?	0.25	0.01	0.27	0.08
18	Do you think your family gives the attention you need?	0.01	−0.14	0.01	**0.83**
19	Do you feel better with this kind of attention?	0.02	0.02	−0.10	**0.71**
17	Has your family recently changed the way they treat you because of a health problem?	−0.01	0.11	0.05	**0.52**
16	Did you have any relationship problems with your family?	0.03	0.08	−0.05	**0.50**
Eigenvalue		6.5	2.3	2.0	1.7
Variance (%)		22.6	7.9	6.9	6.0
Cronbach's Alpha		0.81	0.77	0.77	0.74

Factor loadings greater than 0.3 are presented in bold.

$r = 0.55$ for item 1 ("Do you have memory problems") to $r = 0.08$ for item 12 ("Did you use to go out and visit friends and family?"). Considering its low correlation and the fact that its removal would lead to a slight increase in internal consistency of the scale ($\alpha = 0.88$), item 12 was excluded from further analyses.

Exploratory factor analysis

The KMO analysis revealed a value of 0.79, indicating that the correlation matrix was suitable for factor analysis.

The examination of scree plot and parallel analysis led to a four-factor solution which accounted for 43.4% of the variance. Results from the pattern and structure matrix were similar; we report the pattern matrix because results are typically more conservative and not inflated by overlap between factors [58, 59]. Table 2 depicts the pattern of rotated factor loadings for this four-factor solution.

As a whole, the four-factor solution of the ASPIDD presented a well-defined structure. With the exception of item #23, which loaded both on factors I and II, items had salient loadings in a single factor exclusively. Items #11, #14 and #30 did not have salient loadings on any factor (hyperplane items). The first factor was responsible for 22.6% of the variance with an eigenvalue of 6.5. This factor consisted of 7 items related to awareness of activities of daily living. Factor loadings

were high and yielded very good internal consistency ($\alpha = 0.81$; mild severity: $\alpha = 0.64$; moderate severity: $\alpha = 0.85$). The second factor explained 7.9% of the variance with an eigenvalue of 2.3, and incorporated 11 associated with awareness of cognitive functioning and health condition. Factor loadings were moderate to high, and internal consistency was good ($\alpha = 0.77$; mild severity: $\alpha = 0.73$; moderate severity: $\alpha = 0.80$). The third factor was responsible for 6.9% of the variance with an eigenvalue of 2.0, and was composed of 4 items related to awareness of emotional state. It had high factor loadings and good level of internal consistency ($\alpha = 0.77$; mild severity: $\alpha = 0.61$; moderate severity: $\alpha = 0.85$). Finally, the fourth factor explained 6.0% of the variance, with an eigenvalue of 1.7, and contained 4 items associated with awareness of social functioning and relationships. It showed high factor loadings and good internal consistency ($\alpha = 0.74$; mild severity: $\alpha = 0.61$; moderate severity: $\alpha = 0.84$).

Hierarchical factor analysis

The second order factor analysis lead to a one factor solution with eigenvalue equal to 2.2, which accounted for 54.1% of the variance, and three other factors with eigenvalues smaller than one (0.83, 0.64 and 0.33, respectively). This result suggests, indeed, that the ASPIDD has a hierarchical factor structure, in which the four lower-order factors loaded on a single higher-order factor. Table 3 shows that the higher-order structure had a good simple structure. Because the Schmid-Leiman procedure allows the higher-order factor to account for as much of the correlation among the items as possible, while the lower-order factors are reduced to residual factors uncorrelated with each other and with the higher-order factor, factor loadings are generally lower than those observed in the original exploratory factor analysis presented in Table 2. Therefore, factor loadings equal to or greater than 0.25 are generally considered satisfactory [56]. The higher-order factor accounted for 51.6% of the variance and yielded salient loading on most items. The four lower-order factors explained relatively less of the variance, with the exception of items loading on Factor IV, and some items loading on Factor II and III. Item loadings across these factors were similar to the pattern observed in Table 2, suggesting the same factor labels, the exception being items from Factor I, which loaded heavily on the higher-order factor. Hyperplane items from the first-order analysis (#11 and #14) loaded better on the higher-order factor. By contrast, item #30 remained without salient loadings on this analysis.

Table 3
Hierarchical ASPIDD structure with loadings for one higher- and four lower-order factors

Item #	Higher-order factor	Lower-order factors			
		I	II	III	IV
20	**0.63**	**0.30**	−0.17	0.04	−0.03
26	**0.58**	**0.25**	−0.12	0.02	0.11
21	**0.57**	0.24	−0.12	0.10	0.02
22	**0.65**	0.22	0.12	−0.05	0.06
28	**0.58**	0.21	0.10	−0.02	−0.08
27	**0.57**	0.17	0.21	−0.07	−0.06
15	**0.51**	0.16	0.01	0.17	−0.08
11	**0.44**	0.11	0.11	0.03	0.13
05	0.23	−0.08	**0.49**	0.01	0.01
04	**0.31**	−0.03	**0.42**	−0.01	0.02
29	**0.50**	0.08	**0.39**	−0.09	0.06
01	**0.49**	0.02	**0.36**	0.18	0.03
24	**0.38**	0.08	**0.33**	−0.18	0.03
13	0.18	−0.05	**0.32**	0.06	−0.06
03	**0.37**	0.02	**0.29**	0.07	−0.02
02	**0.38**	0.02	**0.27**	0.09	0.05
23	**0.48**	0.11	**0.26**	−0.05	−0.01
25	0.23	−0.06	**0.25**	0.19	0.08
10	**0.34**	0.05	0.24	0.01	−0.03
30	0.24	−0.01	0.19	0.13	−0.03
09	**0.45**	−0.01	−0.01	**0.69**	0.11
08	**0.37**	0.09	0.03	**0.60**	−0.03
07	**0.51**	0.07	0.05	**0.42**	−0.08
06	**0.41**	0.09	0.03	**0.39**	−0.10
14	0.41	0.01	0.01	0.23	0.08
18	0.19	0.01	−0.10	0.01	**0.78**
19	0.21	−0.01	0.01	−0.08	**0.67**
17	**0.26**	−0.01	0.08	0.04	**0.49**
16	0.22	0.01	0.06	−0.04	**0.47**
Variance (%)	51.6	4.3	14.4	13.8	15.9

Factor loadings greater than 0.25 are presented in bold.

Correlations between ASPIDD factors

As shown in Table 4, ASPIDD lower-order factors were modestly correlated with each other. In particular, Factor IV showed overall weak correlations with other factors, while correlations between Factors I, II and III were moderate. Similarly, the higher-order factor showed moderate to strong correlations with lower-order factors I, II, and III, and a low to moderate correlation with factor IV.

Relationship between ASPIDD factors and clinical variables

Pearson's correlations were calculated to explore the relationship between total/subscale ASPIDD scores and clinical variables, such as depression, functional disability, quality of life, caregiver burden, and years since onset. To avoid inflation of family-wise error rate, *p*-values were adjusted with Bonferroni-Hochberg

Table 4
Correlations between higher- and lower-order ASPIDD factors

Variable	Higher-order factor	Lower-order factors			
		I	II	III	IV
Higher-order factor	1.00				
Factor I	0.94	1.00			
Factor II	0.71	0.63	1.00		
Factor III	0.58	0.50	0.36	1.00	
Factor IV	0.35	0.30	0.18	0.26	1.00

Table 5
Correlations between ASPIDD subscales and clinical variables

Variable	FAQ	Cornell	QoL	Zarit	Years since onset
ASPIDD total	**0.42**	0.04	0.11	**0.30**	0.13
ADL	**0.32**	0.03	0.15	0.17	0.12
Cognitive	**0.41**	0.03	0.15	**0.33**	0.13
Affective	**0.21**	0.03	0.03	0.11	0.03
Social	0.17	−0.01	−0.03	0.20	0.04

Significant results are presented in bold. ASPIDD, Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia; ADL, Activities of Daily Living; FAQ, Pfeffer Functional Activities Questionnaire; Cornell, Cornell Scale for Depression in Dementia; QoL, Quality of Life in Alzheimer's Disease scale; Zarit, Zarit Burden Interview.

corrections. Results can be seen in Table 5. Depression, quality of life, and years since onset did not show significant correlations with ASPIDD total or subscores. By contrast, functional disability was positively correlated with total ASPIDD scores ($r = 0.42$, $p < 0.001$), unawareness of activities of daily living ($r = 0.32$, $p < 0.001$), cognitive functioning and health condition ($r = 0.41$, $p < 0.001$), and emotional state ($r = 0.21$, $p = 0.040$). Similarly, caregiver burden was correlated with total ASPIDD scores ($r = 0.30$, $p < 0.001$) and unawareness of cognitive functioning and health condition ($r = 0.31$, $p < 0.001$).

DISCUSSION

The present study is the first evaluation of the psychometric properties and latent structure of the ASPIDD, suggesting that the scale is a reliable measure of awareness of disease. Cronbach's alpha was high ($\alpha = 0.87$), indicating good to excellent internal consistency of the scale. Also, when we divided the Cronbach's alpha for each dementia severity group; generally, consistency remained high, with higher consistency obtained with the moderate dementia severity group ($\alpha = 0.84$). Moreover, item-total correlations coefficients were within acceptable levels, suggesting the adequacy of the ASPIDD items. In line with some previous research [23, 29, 33], our results were also in agreement with the view that awareness of disease is a construct with multiple dimensions. The first exploratory factor analysis detected four dimensions related to awareness of activities of daily living, awareness of cognitive functioning and health condition, awareness of emotional state, and awareness of social functioning and relationships. Item loadings were high and, generally, restricted to a single factor domain. Second-order exploratory factor analysis indicated that the four lower-order factors loaded onto a single higher-order factor. Most items yielded expressive loadings in the higher-order factor. Moreover, the high-order factor accounted for more than half of the variance.

The higher-order factor showed moderate to strong correlations with lower-order factors I (awareness of activities of daily living), II (awareness of cognitive functioning and health condition), and III (awareness of emotional state), and a low to moderate correlation with factor IV (awareness of social functioning and relationships). Factor II was marked for an apparent heterogeneity between items of awareness of cognitive functioning (#4 Have you already got lost in places you know?; #5 Do you have difficulties in recognizing persons or things?) and awareness of level of autonomy and health condition (#14 Do you go shopping alone?, #3 Has anybody already told you what you have?, #2 Do you think you have a disease?), however factor loadings were moderate to high, and internal consistency was good ($\alpha = 0.77$; mild severity: $\alpha = 0.73$; moderate severity: $\alpha = 0.80$). In addition, most of the variance of the full scale is explained by Factors I and II. In other words, unawareness may be essentially a phenomenon related to cognition and ADL. This is in agreement with previous work by Starkstein and colleagues [23], in which awareness in people with AD refers to the lack of recognition of deficits on instrumental or basic ADL, behavioral changes, and mood problems. The current results are also in agreement with studies which suggest a relative independence between awareness levels for different objects [29].

Additionally, Factor IV (awareness of social functioning and relationships) was relatively independent from the higher-order factor, which may be due to a lack of relationship between awareness of social function and general awareness. Agreement between patient and caregiver can be due to awareness, if the patient is fully aware of a deficit as rated by the caregiver, but it can be also caused by the lack of any noticeable deficit to be recognized despite an impaired capacity for awareness [6]. The degree of deficit is thus an inherent confounding factor in comparisons

of discrepancies across domains, and varying degrees of discrepancy may be due to differences in awareness, but they may equally result from different degrees of deficit; for example, memory would have been markedly affected from the very beginning, whereas everyday activities are likely to become increasingly affected as people progress from the mild to moderate stages of dementia, and difficulties with social functioning may start to become evident at this time [3]. Future work should examine further domain-specific trajectories of awareness.

Moderate correlations were found between functional disability and unawareness of disease. It has been demonstrated that PwD commonly show unawareness for memory dysfunction [9, 60] and ADL deficits [29]. As predicted by theoretical models and some empirical data [12], it is possible that unawareness is caused by executive dysfunction, which is also known to have an impact in performance in ADL. The lack of recognition of changes in activities of daily living have great impact on the management and the safety of PwD with risk behaviors (such as driving or cooking), and increases caregiver burden [5, 22].

The operationalization of the awareness concept deserves to be further discussed, as patient and caregiver often disagree about the severity of cognitive deficits due to several possible factors. Recently, a study found that non-cognitive factors such as disease awareness, caregiver burden, and depressive symptoms play an important role in the differences between self-reported and caregivers' ratings in AD [61]. The analysis of the discrepancy between patients and caregivers suggests that patients tend to underestimate their difficulties because of impairment in awareness whereas caregivers often overestimate the cognitive deficits of patients, depending on their degree of stress [27, 33, 62]. However, Leicht et al. [13] indicated that results from clinical rating and questionnaire discrepancies are comparable, as these correlate strongly. We found that caregiver burden was correlated with total ASPIDD scores and unawareness of cognitive functioning. In fact, the degree of accuracy with which caregivers rate relational domains may be very different to that with which they rate cognitive deficits. Although assessing awareness has some difficulties, it is clear that caregivers' responses are determined by their perception of the extent to which the care recipient is aware.

The present study has several limitations which should be acknowledged. Firstly, we did not study the convergent validity of the ASPIDD as compared to any other awareness assessment. Secondly, the cross-sectional design of the study is not appropriate to infer causality between unawareness of disease and the ASPIDD dimensions. Therefore, future work employing a longitudinal design is important in order to further evaluate the relationship between impairment in awareness and the underlying dimensions of the ASPIDD construct. Furthermore, we have neither assessed PwD neuropsychiatric symptoms and neuropsychological data, which would permit the relationship with the nature and construct of the ASPIDD, nor the history of neurological and psychiatry disorders in caregivers.

CONCLUSION

To the best of our knowledge, there is no standardized awareness of disease instrument such as the ASPIDD, covering multiple domains. Our results indicate that the ASPIDD is a reliable measure of awareness of disease. Factor analysis of the scale identified four dimensions related to awareness of ADL, cognitive functioning and health condition, emotional state, and social functioning and relationships. Differences across dimensions may be thus likely to arise from impairment mainly in cognition and ADL in conjunction with varying degrees of deficit.

Investigating the underlying mechanisms associated with the differences and degrees of unawareness will allow for enhanced understanding of risk factors associated with them, and also perhaps for more specific PwD management strategies based on unawareness levels.

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