Awareness of Self and Disease Assessment (ASDA): Development and validation of a subjective measure in people with Alzheimer's disease

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Running title: ASDA: development and validation

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Abstract:

Background: People with Alzheimer’s disease (PwAD) remain able to speak coherently about their daily life for a long time, and their level of awareness could be determined through their discourse. In a grounded-theory approach, awareness of self and awareness of disease are intertwined and can be observed through three domains: mechanisms, objects and modes of expression.

Objectives: Based on preliminary results, in this article, we present the ASDA (Awareness of Self and Disease Assessment), a new subjective measurement tool for awareness in PwAD. To consider its use in research and practice, we initially performed validation analyses, including internal consistency, test-retest reliability and interrater reliability analyses.

Methods: The new assessment tool consists of a semi-structured interview and ratings of 22 items divided into three categories. As part of our observational study, we assessed a sample of 28 PwAD who participated in four interviews (one every two weeks).

Results: The ASDA shows good homogeneity within the domains of awareness and a certain degree of stability between two measurement times and between investigators. Missing values in the results provided information regarding awareness levels within and across the subjects.

Conclusions: The results suggest that awareness could be assessed through subjective experience without reference to a comparison.

Keywords: Alzheimer’s disease, anosognosia, awareness, self, self-assessment

INTRODUCTION

Awareness in Alzheimer's disease (AD) can be assessed with an explicit or implicit system of reference. An explicit system refers to an informant (e.g., a caregiver and/or health professional) or performance. An implicit system refers to clinician ratings. Although such assessments are very useful and standardized and provide some information about the level of awareness, they do not adequately reflect the daily experiences of people with Alzheimer's disease (PwAD). However, research has shown that PwAD remain able to talk about their experiences with the disease for a long time [1,2]. Based on these findings and a grounded theory approach to disease awareness [3], we develop a new subjective assessment tool for awareness in PwAD and verify its psychometric properties (i.e., internal consistency, test-retest reliability and interrater reliability). This study provides initial information to address the challenge of the implementation of person-centered approaches in care [4].

Assessing awareness through a system of reference

Discrepancies between the ratings of informants and PwAD

A preliminary approach, which is the most common method in basic research [5], considers discrepancies between informants' and PwAD's ratings of the disease or newly perceived difficulties [6] (e.g., the Anosognosia Questionnaire-Dementia [7–9]; Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia [10]). The informant may be a caregiver [11–14] or a clinician [15,16]. This approach considers many objects, such as functional abilities [17], cognitive functions [18–21], health [14], autonomy [17,22,23], and emotional and social functioning [24]. This first paradigm (i.e., discrepancies between informants' and PwAD's ratings) provides a broad understanding of awareness levels in AD. This method considers caregiver feedback (in a nursing home or at home) but has some limitations. For instance, caregivers may deny the existence or lack knowledge of the disease. Additionally, clinicians may overestimate the deficits of PwAD [16]. Some factors may influence related assessments [25], such as relationships, time spent with PwAD, psychological state [26], and knowledge of the disease [16]. The prediction-performance paradigm was proposed to address these limitations.

Prediction-performance discrepancies

Another type of assessment of the awareness of disease has been presented [3] in which discrepancies between the predictions of PwAD and their performance on an objective task are examined (e.g., the Multidimensional Isomorphic Simple Awareness Assessment (MISAwareness) [27,28]; the Memory Awareness Rating Scale (MARS) [29]; the MARS-Adjusted [30]). This prediction-performance paradigm is considered "*experimentally more correct*" because it avoids all subjective and emotional biases [31], although it also has limitations. For instance, differences may exist between the actual task and mental representations. Moreover, most tasks are cognitive and specifically assess memory performance [6,32]. Although the MISAwareness was developed to avoid these limitations [27], the paradigm still focuses on cognitive functions without considering daily life activities.

These two methods based on comparison are the most commonly used, either independently or in combination, in research on awareness in AD. Recently, two studies [33,34] have relied on clinician ratings to add information to these explicit systems of reference.

From assessing awareness with an implicit system of reference toward the subjective experiences of PwAD

Clinical ratings are used in assessments based on PwAD’s responses [6] (obtained with a questionnaire, a semi-structured interview [35,36] or observation [37,38]). These clinical ratings have good psychometric properties and seem to be convenient for care in nursing homes. Moreover, such assessments can address items ranging from cognitive function to self-perception. The first validated assessment was the Clinical Insight Rating [39]. Gil et al. (2001) [40] suggested an assessment with a broader perspective on awareness, ranging from awareness of the disease to awareness of self, which consists of 14 questions regarding general information, emotions, relationships and abilities. This assessment includes awareness of self, and this clinician rating considers the experiences of PwAD. Nevertheless, this type of method has limitations. The information required to determine the level of awareness is obtained from clinical appointments, which are framed by pathological guidelines. Consequently, an impaired level of awareness is considered a symptom. PwAD are defined only as “Aware” or “Unaware” according to their scores. To summarize, clinician ratings, which more closely reflect PwAD’s experiences, constitute an implicit system of reference: knowledge of the disease and generalization of its evolution. Such ratings do not fully consider PwAD’s discourse and their daily experiences to understand their levels of awareness.

One purpose of person-centered approaches is to optimally reflect the subjective experiences of PwAD that we regard as “*a return to the things themselves*” [41]. From this perspective on subjective experiences, Johannessen, Engedal, Haugen, Dourado, and Thorsen (2018) and Emery Trindade, Santos, Lacerda, Johannessen and Dourado (2018) [1,2] showed that PwAD are still able to talk about their experiences with the disease. Thus, the consideration of how PwAD live with the disease and perceive themselves seems helpful for determining their awareness of the disease. To study PwAD’s experiences and how they make sense of their situation, Billiet et al. (2009) [3] adopted a phenomenological approach and focused on PwAD’s dialogue to model the process of awareness of the disease. With this grounded theory approach, they observed an intertwined relationship between awareness of the disease and awareness of self. The authors identified a comprehensive model organized into three categories: objects, mechanisms and modes of expression. The objects represent the basis of changes and new information perceived by PwAD (e.g., the environment, emotions, the body, communication, autonomy, identity changes, loss of cognitive abilities and the disease). The mechanisms are the processes of awareness (e.g., observation of the environment, perception of the look of others, comparison between the past and the present, metacognition and confrontation with difficulties). The modes of expression are how PwAD express their awareness of the disease and/or self (e.g., denial, bewilderment, attribution, description, judgment, recognition of the need for help, the use of coping strategies and confirmation of the disease). In this category, awareness is considered using only verbal reports that can reflect explicit awareness [42]. These initial approaches demonstrate the possibility of considering PwAD's subjective experiences in awareness assessments.

To summarize, many scales with different methodologies assess awareness in PwAD. Recently, studies have shown the importance and possibility of considering the subjectivity and discourse of PwAD in relation to the disease [1,2]. In addition, a phenomenological study introduced a new perspective for considering awareness in a subjective manner by combining the self and the disease [3]. Based on the above findings, we aim to propose and validate a new subjective measurement of awareness in AD. With this assessment, we aim to reflect the experiences of PwAD as closely as possible. Here, we present our original rating instrument and an initial statistical validation.

METHODS

Design

The aim of this study was to develop and validate a subjective measure of awareness in PwAD. This observational study was conducted with nursing home residents suffering from Alzheimer's disease. Each participant provided written informed consent. Ethical approval was granted by the University of Lille ethics committee.

Participants

The participants were residents in seven nursing homes in the north of France for three months or more. The criterion of three months or more reduced the influence of a new environment on awareness. To be included, participants had to have been diagnosed with Alzheimer's disease as described by the National Institute on Aging-Alzheimer's Association clinical criteria [43]. There was no criterion regarding disease severity, and there was no minimum or maximum score on the Mini-Mental State Examination (MMSE). To be included, participants had to be native French speakers or had to speak in French with the investigator. Finally, they had no previous psychiatric illness, history of traumatic brain injury or cerebrovascular disease.

The sample consisted of 28 participants (*Mean (M)* age = 85.21 years, *SD* = 6.71), including 23 women (aged 70 years to 96 years; *M* = 86.04 years, *SD* = 5.83) and five men (aged 66 years to 90 years; *M* = 85.25 years, *SD* = 5.25).

Each participant had four individual interviews (one interview every two weeks). The initial data were collected from one investigator who interviewed and rated the participant. The second investigator also rated each interview using the audio records and transcriptions. We obtained 112 scores for each item in our dataset. The dataset was used for all statistical analyses except to measure test-retest reliability. This last analysis was based on data from the first and the second interviews.

Measure

Awareness of Self and Disease Assessment (ASDA)

The ASDA, or Awareness of Self and Disease Assessment, is a subjective measure of awareness in PwAD based on the initial results obtained by Billiet et al. (2009) [3]. It is composed of a semi-structured interview and an associated rating. A semi-structured interview refers to a meeting in which the interview guide covers many topics and is composed of questions determined by the knowledge of these topics in relation to the object of the study to collect data [44]. For the initial data collection in this study, each participant engaged in a semi-structured interview that included themes such as mood, emotions, well-being (physical and psychological), daily life, self-perception (body, personality), family, friends, relationship changes, cognitive functions, memory loss, elderly experience, disease and expectations for the future. The interviews were conducted by one of two investigators trained in semi-structured interviews. The interviews did not have to follow each theme, and the main questions were evasive, such as “How are you?”, “What are you doing today?” or “Talk to me about you”. Moreover, during the interview, the investigator mainly used reformulations or repetitions. The objective of the ASDA was to follow only the experience of PwAD and what they wanted/were able to say about it. The ASDA was designed to be as close as possible to the subjective experience of having the disease.

Subsequently, each interview was transcribed and rated. In detail, Billiet et al. (2009) [3] proposed a theoretical approach to disease experience composed of three categories. To assess awareness based on the interview, our scale followed these categories. Each semi-structured interview was rated with objects, mechanisms and modes of expression. The assessment tool was composed of 22 items: nine for the objects, five for the mechanisms and eight for the modes of expression (Table 1). Each mechanism and mode of expression item was rated on a 6-point Likert scale (1: “Minimally present”, 2:”Slightly present”, 3: “Mildly present”, 4: “Moderately present”, 5: “Strongly present” and 6:“Extremely present”). Each object item was rated on a 6-point Likert scale (1: “Strong unawareness”, 2: “Mild unawareness”, 3: “Slight unawareness”, 4: “Slight awareness, 5: “Mild awareness” and 6: “Strong awareness”). When an item was not evoked during the course of the interview, it was noted as “Not Assessed”. A higher rating was associated with a higher level of awareness. No cut-off score was applied to the ratings; the ASDA provides “a profile of awareness” (i.e., a map of awareness) for each person with AD.

[Table 1 here]

Data analysis

All statistical analyses were performed with R (version 3.5.2) and the packages “psych”, “FactoMineR” and “MissMDA”. For each investigator and item, preliminary analyses were conducted to verify the statistical assumption of normality (graphically and with Shapiro-Wilk tests). With the small sample ($N = 28$), normality was not found, so Spearman correlations were used for test-retest reliability. Internal consistency reliability was examined with Cronbach’s alpha. Interrater reliability was observed between the two investigators with Cohen’s kappa and intraclass coefficient correlation (ICC).

RESULTS

Preliminary analysis

Missing values

The ASDA is a subjective measure based only on what PwAD were able to say. Consequently, this method resulted in missing values. All ASDA items had a minimum of one missing value (0.9% of rating items) and a maximum of 53 missing values (47.3% of rating items) (Table 2). The strong presence of missing values (> 30%) for some items (O4: Communication, O5: Autonomy, O7: Loss of cognitive abilities, E6: Recognize the need for help, E7: Use of coping strategies and E8: Confirmation of the disease) introduces clinical consequences about the inter- and intravariabilities of awareness for PwAD in nursing homes. For this study, missing values influenced the quality of the analysis. To address the loss of information, we used the “FactoMineR” and “MissMDA” packages to impute data.

[Table 2 here]

Internal consistency

Internal consistency was obtained by assessing Cronbach’s alpha values. For each investigator, Cronbach’s alpha was high (>.77) for all ASDA scales and for each category (objects, mechanisms and modes of expression) (Table 3). While the Cronbach’s alpha values differed between investigators, lower values were for the “Objects”, and higher values were for the “ASDA” scales. Internal consistency was confirmed for the ASDA.

[Table 3 here]

Test-retest reliability

Test-retest reliability was examined with Spearman correlations using the ratings from the first and the second interviews of all 28 participants (Table 2). Each participant underwent four interviews (one every two weeks) to obtain information for test-retest reliability and to examine fluctuations in awareness in another study protocol. This analysis was performed for each investigator. At the two-week follow-up, test-retest correlations showed that the ASDA had good test-retest reliability ($p < .05$). However, for investigator 1, items E4: Self-description and E7: Use of coping strategies had lower correlations ($r = .13$; $p > .05$ and $r = .29$; $p > .05$, respectively). For investigator 2, only item E7 had a lower correlation ($r = .17$; $p > .05$).

Interrater reliability (ICC and Cohen's kappa)

Interrater reliability was first assessed with Cohen's kappa to measure agreement regarding the presence or absence of items in the discourse of PwAD. A second analysis was conducted with intraclass correlation coefficients to measure agreement in the level of item rating between the investigators. Seven items had mild agreement (Cohen's kappa between .46 and .61; M2: Perception of the look of others, O5: Autonomy, O9: The disease, E3: Attribution, E4: Self-description, E6: Recognize the need for help, E7: Use of coping strategies, E8: Confirmation of disease). Six items had low agreement (Cohen's kappa between .21 and .39; M4: Metacognition, M5: Confrontation of difficulties, O4: Communication, O5: Autonomy, O7: Loss of cognitive abilities, E2: Bewilderment). There was no agreement between the investigators regarding the absence or presence of items in the discourse of PwAD (Table 2). These results were skewed by missing values introduced by the methodology. One investigator interviewed the participants four times (i.e., established a relationship) and had access to information about health professionals and care in nursing homes. The second investigator had only the audio recording and transcription without additional information.

This methodological bias was more relevant for the items than for the level of rating for each item; that is, intraclass correlation coefficients showed good interrater reliability (ICC between .40 and .85), with the exception of item O4.

Correlations (Spearman correlations with age and MMSE score)

Correlations were assessed to observe potential relations between age, MMSE scores and awareness as assessed with the domains of the ASDA. These correlations were established in the first ASDA interview for each participant (n = 28), and the ratings were assigned by an investigator who had not directly interviewed the participant. The data are available in Table 3.

Only the "Mechanisms" domain of the ASDA had a significant correlation ($r = .34$, $p < .05$) with the MMSE score. For the other domains, the correlations were weaker and non-significant. No significant correlation was found for age.

DISCUSSION

In this article, we aimed to draw upon Billiet et al.'s (2009) [3] results to propose a new structure for a rating of awareness that investigates multiple domains. In this assessment, we wanted to stay as close as possible to the experience of PwAD and have attempted to respond to the challenge of the implementation of person-centered approaches in care. These objectives address the limitations of other approaches, such as the lack of a person-centered approach in comparative assessments or a tendency to focus on one object of awareness. This article describes this original rating tool and an overview of its feasibility.

The ASDA is based on grounded theory and PwAD's comments about their daily lives with the disease. This new rating system is based on clinical investigations, which allow close representations of PwAD's experiences. In this study, we observed that PwAD could self-report their daily lives and confirmed the possibility and the need to consider subjectivity during care [45–50]. Moreover, the assessment of awareness with the ASDA provided information about the broader personal daily experiences of PwAD from their perspective. The ASDA extends beyond disease symptoms by investigating several aspects of the respondents' daily lives (e.g., mood and relationships).

The ASDA satisfies the social policy of implementing a person-centered approach with good psychometric properties (internal consistency, test-retest reliability and interrater reliability) for PwAD in an institution. We provided initial statistical information regarding the feasibility of the ASDA and observed good internal consistency for all items and for each category. Although the ASDA is based on a grounded approach using the discourses of PwAD instead of theoretical definitions, it revealed common processes of awareness in each person. For the most part, the ASDA also had good interrater reliability and test-retest reliability. These two psychometric indicators suggest that the ASDA is not far removed from the processes of awareness as experienced by each PwAD regardless of the investigator or temporality. With regard to interrater reliability, the analyses were influenced by the methodology. Although the reliability of the level of awareness was good, there was disagreement between the investigators regarding the absence/presence of items during the interviews. This discrepancy may be explained by the accessibility of information about the participants. Whereas one investigator had full information (he/she met the participant four times, met health professionals, and had information about care in the institution), the other investigator had only the transcriptions and audio recordings. With this material, the second investigator could not appreciate all the information that was available to the first investigator, which led to differences in ratings. This bias highlights the importance of the relationship created between clinicians and PwAD and the accessibility of other types of information (e.g., nonverbal behaviors, communication with health professionals and information on care in an institution) in the assessment of awareness. A future study could measure this bias by providing the same information to each investigator (e.g., transcriptions and audio or video recordings).

Considering the characteristics of the sample, the level of awareness determined by the ASDA is not associated with psychosocial factors such as age. This absence of an association can be explained by coping strategies developed by both younger and older participants with aging (e.g., to minimize their abilities and to anticipate and adjust to changes) [51]. Similarly, the level of awareness is not associated with the cognitive deficit assessed by the MMSE, except for the mechanisms assessed by investigator 1. These results are inconsistent with those of other studies [52,53]. These differences in the findings can be explained by the type of methodology used to assess awareness. Previous studies mainly assessed awareness through a system of reference with a greater emphasis on cognitive functioning than our phenomenological approach. Future research should explore this methodological influence.

This study has some limitations mainly related to the characteristics of the sample (e.g., the severity of the disease, gender, neuropsychiatric symptoms or personality traits). As reported in previous studies, cognitive functions and disease severity [52,53] may influence awareness. However, we did not verify the influences of objective indicators except the MMSE. Considering the gender distribution of our sample (more women than men), we could not verify the influence of gender [54]. A future protocol to specify awareness profiles according to individual traits should consider neuropsychiatric symptoms (e.g., the NeuroPsychiatric Inventory [55,56]) or personality traits (e.g., the Interpersonal Adjectives Scales [57]).

Additionally, given the focus on the development of the assessment, the present study did not explore information about the concurrent validity of the ASDA. Future studies could conduct this analysis through a comparison with another assessment in the PwAD population. This suggests two possibilities. The first possibility is to compare the ASDA with a similar assessment, such as the measure of Gil et al. (2001) [40]. Combined with the initial statistical information in the present study, this comparison will provide a complete validation of the ASDA. The second possibility is to compare the ASDA with a different type of assessment, such as prediction-performance paradigms (e.g., the MISAwareness [27]), or discrepancies between the ratings of PwAD and informants (e.g., ASPIDD [2,10]). The concurrent validity will include only a few items in common but will allow a broader understanding of awareness. A broader understanding ranging from cognitive functions to daily experiences may provide a complete awareness cluster for PwAD. It will also satisfy the clinical objective of a person-centered approach in Alzheimer’s disease. Moreover, from a theoretical perspective, this comparison of methods will provide information about the concept of awareness evaluated in each method (i.e., whether and how they are similar and/or different).

In this study, we used a dataset composed of 112 scores from 28 participants who were each interviewed four times. We used this dataset without taking into account repeated assessments except for test-retest reliability. This choice was the consequence of variability in the occurrence of particular themes. For each participant, we could not rate all items of the ASDA in one interview. Therefore, we could note the absence of items in the rating. The lack of items in the rating does not reflect unawareness but rather reflects an absence in the discourse during the assessment. This temporal dependency could be induced by individual (e.g., cognitive impairment, personality, fatigue), environmental (e.g., adapted, stimulating) and/or social factors (e.g., relationship with the investigator). Despite this influence on the precision of the statistical analysis, we obtained clinical information. First, there are inter- and intraindividual variabilities of awareness over time. Second, more than one interview seems necessary to address all the processes of awareness in research and in practice. A more detailed analysis of the different clusters obtained and the level of temporal fluctuation of awareness could help to enhance the personalization of care in nursing homes. In France, for example, upon entry to a nursing home, each PwAD, with the help of health professionals, establishes a "*life project*" [58]. This project, which is regularly revised, represents guidelines for care and activities in the institution and depends on cognitive impairments, autonomy, and self-preferences and their evolution. There is no assessment of awareness in these indicators, although Rice, Howard, & Huntley (2019) [4] argued for the need to understand the perspective of PwAD to improve the quality of care. The ASDA could easily be incorporated into these protocols because the ASDA can be conducted by all care staff (e.g., psychologists, doctors, nurses), who only need to understand the interview and rating procedures. For practicing professionals, the accessibility of the ASDA procedure would provide a better understanding of the disease experience of PwAD according to their level of awareness. This would address the urgency of understanding the subjective experience of PwAD in care [4] and "*acknowledging the person behind the* *patient*" [59]. Going beyond this main advantage of the personalization of care, a better understanding of awareness could also produce benefits such as reducing professionals' stress during care [37,60].

Although recent studies have preferred the advantages of assessments with reference to comparison, we chose to develop and observe the feasibility of a self-report assessment of the awareness of PwAD. The study showed that PwAD can talk about their daily life with the disease and that their discourse can be used in care. The appreciation of the central place of the experience of PwAD may help to meet social policy healthcare perspectives such as those currently being developed in dementia-friendly communities.

Acknowledgments: The LABEX (excellence laboratory, program investment for the future) DISTALZ (Development of Innovative Strategies for a Transdisciplinary Approach to Alzheimer's disease) and regional council of Hauts-de-France supported this work.

Conflict of interest: The authors have no conflicts of interest to report.

REFERENCES

[1] Johannessen A, Engedal K, Haugen PK, Dourado MCN, Thorsen K (2018) “To be, or not to be”: experiencing deterioration among people with young-onset dementia living alone. *Int. J. Qual. Stud. Health Well-Being* **13**, 1490620.

[2] Emery Trindade PG, Santos RL, Lacerda IB, Johannessen A, Nascimento Dourado MC (2018) Awareness of disease in Alzheimer’s disease: what do patients realize about their own condition? *Aging Ment. Health* 1–8.

[3] Billiet C, Antoine P, Nandrino JL, Szafraniec CR, Cousin C (2009) Developing a grounded theory approach to conceptualising awareness in elderly people suffering from Alzheimer type dementia.

[4] Rice H, Howard R, Huntley J (2019) Professional caregivers’ knowledge, beliefs and attitudes about awareness in advanced dementia: a systematic review of qualitative studies. *Int. Psychogeriatr.*

[5] Chavoix C, Insausti R (2017) Self-awareness and the medial temporal lobe in neurodegenerative diseases. *Neurosci. Biobehav. Rev.* **78**, 1–12.

[6] Clare L (2004) Awareness in early-stage Alzheimer’s disease: a review of methods and evidence. *Br. J. Clin. Psychol.* **43**, 177–196.

[7] Gambina G, Valbusa V, Corsi N, Ferrari F, Sala F, Broggio E, Condoleo MT, Surdo V, Errera P, Cagnin AC, Moretto G, Moro V (2015) The Italian validation of the Anosognosia Questionnaire for Dementia in Alzheimer’s disease. *Am. J. Alzheimers Dis. Other Demen.* **30**, 635–644.

[8] Sato J, Nakaaki S, Murata Y, Shinagawa Y, Matsui T, Hongo J, Tatsumi H, Akechi T, Furukawa TA (2007) Two dimensions of anosognosia in patients with Alzheimer’s disease: reliability and validity of the Japanese version of the Anosognosia Questionnaire for Dementia (AQ-D). *Psychiatry Clin. Neurosci.* **61**, 672–677.

[9] Turró-Garriga O, Garre-Olmo J, López-Pousa S, Vilalta-Franch J, Reñé-Ramírez R, Conde-Sala JL (2014) Abridged Scale for the Screening Anosognosia in Patients With Dementia. *J. Geriatr. Psychiatry Neurol.* **27**, 220–226.

[10] Dourado MCN, Mograbi DC, Santos RL, Sousa MFB, Nogueira ML, Belfort T, Landeira-Fernandez J, Laks J (2014) Awareness of disease in dementia: factor structure of the assessment scale of psychosocial impact of the diagnosis of dementia. *J. Alzheimers Dis. JAD* **41**, 947–956.

[11] Fogarty J, Almklov E, Borrie M, Wells J, Roth RM (2017) Subjective rating of executive functions in mild Alzheimer’s disease. *Aging Ment. Health* **21**, 1184–1191.

[12] Maki Y, Amari M, Yamaguchi T, Nakaaki S, Yamaguchi H (2012) Anosognosia: patients’ distress and self-awareness of deficits in Alzheimer’s disease. *Am. J. Alzheimers Dis. Other Demen.* **27**, 339–345.

[13] Mårdh S, Karlsson T, Marcusson J (2013) Aspects of awareness in patients with Alzheimer’s disease. *Int. Psychogeriatr.* **25**, 1167–1179.

[14] Phung TKT, Siersma V, Vogel A, Waldorff FB, Waldemar G (2018) Self-rated versus Caregiver-rated Health for Patients with Mild Dementia as Predictors of Patient Mortality. *Am. J. Geriatr. Psychiatry Off. J. Am. Assoc. Geriatr. Psychiatry* **26**, 375–385.

[15] Mangone CA, Hier DB, Gorelick PB, Ganellen RJ, Langenberg P, Boarman R, Dollear WC (1991) Impaired insight in Alzheimer’s disease. *J. Geriatr. Psychiatry Neurol.* **4**, 189–193.

[16] Snow AL, Norris MP, Doody R, Molinari VA, Orengo CA, Kunik ME (2004) Dementia Deficits Scale. Rating self-awareness of deficits. *Alzheimer Dis. Assoc. Disord.* **18**, 22–31.

[17] Vasterling JJ, Seltzer B, Watrous WE (1997) Longitudinal assessment of deficit unawareness in Alzheimer's disease. *Neuropsychiatry. Neuropsychol. Behav. Neurol.* **10**, 197–202.

[18] Dekkers M, Joosten-Weyn Banningh EWA, Eling P a. TM (2009) [Awareness in patients with mild cognitive impairment (MCI)]. *Tijdschr. Gerontol. Geriatr.* **40**, 17–23.

[19] Hanyu H, Sato T, Akai T, Sakai M, Takasaki R, Iwamoto T (2007) [Awareness of memory deficits in patients with dementias: a study with the Everyday Memory Checklist]. *Nihon Ronen Igakkai Zasshi Jpn. J. Geriatr.* **44**, 463–469.

[20] Kalbe E, Salmon E, Perani D, Holthoff V, Sorbi S, Elsner A, Weisenbach S, Brand M, Lenz O, Kessler J, Luedecke S, Ortelli P, Herholz K (2005) Anosognosia in very mild Alzheimer's disease but not in mild cognitive impairment. *Dement. Geriatr. Cogn. Disord.* **19**, 349–356.

[21] Stewart G, McGeown WJ, Shanks MF, Venneri A (2010) Anosognosia for memory impairment in Alzheimer's disease. *Acta Neuropsychiatr.* **22**, 180–187.

[22] Cramer K, Tuokko HA, Mateer CA, Hultsch DF (2004) Measuring awareness of financial skills: reliability and validity of a new measure. *Aging Ment. Health* **8**, 161–171.

[23] Gallo DA, Cramer SJ, Wong JT, Bennett DA (2012) Alzheimer's disease can spare local metacognition despite global anosognosia: revisiting the confidence-accuracy relationship in episodic memory. *Neuropsychologia* **50**, 2356–2364.

[24] Lacerda IB, Santos RL, Belfort T, Neto JPS, Dourado MCN (2018) Patterns of discrepancies in different objects of awareness in mild and moderate Alzheimer's disease. *Aging Ment. Health* 1–8.

[25] Mograbi DC, Ferri CP, Stewart R, Sosa AL, Brown RG, Laks J, Morris RG (2015) Neuropsychological and behavioral disturbance correlates of unawareness of memory impairment in dementia: a population-based study. *J. Geriatr. Psychiatry Neurol.* **28**, 3–11.

[26] Edmonds EC, Weigand AJ, Thomas KR, Eppig J, Delano-Wood L, Galasko DR, Salmon DP, Bondi MW (2018) Increasing Inaccuracy of Self-Reported Subjective Cognitive Complaints Over 24 Months in Empirically Derived Subtypes of Mild Cognitive Impairment. *J. Int. Neuropsychol. Soc. JINS* **24**, 842–853.

[27] Antoine P, Nandrino J-L, Billiet C (2013) Awareness of deficits in Alzheimer's disease patients: analysis of performance prediction discrepancies. *Psychiatry Clin. Neurosci.* **67**, 237–244.

[28] Avondino E, Antoine P (2016) Heterogeneity of Cognitive Anosognosia and its Variation with the Severity of Dementia in Patients with Alzheimer's Disease. *J. Alzheimers Dis. JAD* **50**, 89–99.

[29] Clare L, Wilson BA, Carter G, Roth I, Hodges JR (2002) Assessing awareness in early-stage Alzheimer's disease: Development and piloting of the Memory Awareness Rating Scale. *Neuropsychol. Rehabil.* **12**, 341–362.

[30] Hardy RM, Oyebode JR, Clare L (2006) Measuring awareness in people with mild to moderate Alzheimer's disease: development of the Memory Awareness Rating Scale--adjusted. *Neuropsychol. Rehabil.* **16**, 178–193.

[31] Dalla Barba G, Parlato V, Iavarone A, Boller F (1995) Anosognosia, intrusions and "frontal" functions in Alzheimer's disease and depression. *Neuropsychologia* **33**, 247–259.

[32] Antoine C, Antoine P, Guermonprez P, Frigard B (2004) Conscience des déficits et anosognosie dans la maladie d'Alzheimer. *L'Encéphale* **30**, 570–577.

[33] Tondelli M, Barbarulo AM, Vinceti G, Vincenzi C, Chiari A, Nichelli PF, Zamboni G (2018) Neural Correlates of Anosognosia in Alzheimer’s Disease and Mild Cognitive Impairment: A Multi-Method Assessment. *Front. Behav. Neurosci.* **12**, 100.

[34] Leicht H, Berwig M, Gertz H-J (2010) Anosognosia in Alzheimer’s disease: the role of impairment levels in assessment of insight across domains. *J. Int. Neuropsychol. Soc. JINS* **16**, 463–473.

[35] Loebel JP, Dager SR, Berg G, Hyde TS (1990) Fluency of speech and self-awareness of memory deficit in alzheimer’s disease. *Int. J. Geriatr. Psychiatry* **5**, 41–45.

[36] Weinstein EA, Friedland RP, Wagner EE (1994) Denial/Unawareness of Impairment and Symbolic Behavior in Alzheimer’s Disease. *Cogn. Behav. Neurol.* **7**, 176.

[37] Clare L, Whitaker R, Woods RT, Quinn C, Jelley H, Hoare Z, Woods J, Downs M, Wilson BA (2013) AwareCare: a pilot randomized controlled trial of an awareness-based staff training intervention to improve quality of life for residents with severe dementia in long-term care settings. *Int. Psychogeriatr.* **25**, 128–139.

[38] Clare L, Whitaker R, Quinn C, Jelley H, Hoare Z, Woods B, Downs M, Wilson B (2012) AwareCare: development and validation of an observational measure of awareness in people with severe dementia. *Neuropsychol. Rehabil.* **22**, 113–133.

[39] Ott BR, Fogel BS (1992) Deficit awareness in dementia: Relevance to the clinical diagnosis of Alzheimer’s disease. *Neurobiol. Aging* **13**, S11.

[40] Gil R, Arroyo-Anllo EM, Ingrand P, Gil M, Neau JP, Ornon C, Bonnaud V (2001) Self-consciousness and Alzheimer’s disease. *Acta Neurol. Scand.* **104**, 296–300.

[41] Ashworth P (2007) Conceptual Fundations of Qualitative Psychology. In *Qualitative Psychology: A Practical Guide to Research Methods* SAGE.

[42] Mograbi DC, Morris RG (2013) Implicit awareness in anosognosia: clinical observations, experimental evidence, and theoretical implications. *Cogn. Neurosci.* **4**, 181–197.

[43] McKhann GM, Knopman DS, Chertkow H, Hyman BT, Jack CR, Kawas CH, Klunk WE, Koroshetz WJ, Manly JJ, Mayeux R, Mohs RC, Morris JC, Rossor MN, Scheltens P, Carrillo MC, Thies B, Weintraub S, Phelps CH (2011) The diagnosis of dementia due to Alzheimer’s disease: recommendations from the National Institute on Aging-Alzheimer’s Association workgroups on diagnostic guidelines for Alzheimer’s disease. *Alzheimers Dement. J. Alzheimers Assoc.* **7**, 263–269.

[44] Kallio H, Pietilä A-M, Johnson M, Kangasniemi M (2016) Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *J. Adv. Nurs.* **72**, 2954–2965.

[45] Brookes RL, Hannesdottir K, Markus HS, Morris RG (2013) Lack of awareness of neuropsychological deficit in cerebral small vessel disease: The relationship with executive and episodic memory functions. *J. Neuropsychol.* **7**, 19–28.

[46] Clare L, Marková I, Verhey F, Kenny G (2005) Awareness in dementia: A review of assessment methods and measures. *Aging Ment. Health* **9**, 394–413.

[47] Clare L, Whitaker CJ, Nelis SM, Martyr A, Markova IS, Roth I, Woods RT, Morris RG (2011) Multidimensional assessment of awareness in early-stage dementia: a cluster analytic approach. *Dement. Geriatr. Cogn. Disord.* **31**, 317–327.

[48] Summa M, Fuchs T (2015) Self-experience in Dementia. *Riv. Int. Filos. E Psicol.* **6**, 387–405.

[49] Weigmann K (2013) Our sense of self. *EMBO Rep.* **14**, 765–768.

[50] Wilson RS, Sytsma J, Barnes LL, Boyle PA (2016) Anosognosia in Dementia. *Curr. Neurol. Neurosci. Rep.* **16**, 77.

[51] Oyebode DJR, Telling AL, Hardy RM, Austin J (2007) Awareness of memory functioning in early Alzheimer's disease: Lessons from a comparison with healthy older people and young adults. *Aging Ment. Health* **11**, 761–767.
[52] Akai T, Hanyu H, Sakurai H, Sato T, Iwamoto T (2009) Longitudinal patterns of unawareness of memory deficits in mild Alzheimer's disease. *Geriatr. Gerontol. Int.* **9**, 16–20.
[53] Baptista MAT, Santos RL, Kimura N, Marinho V, Simões JP, Laks J, Johannenssen A, Barca ML, Engedal K, Dourado MCN (2019) Differences in Awareness of Disease Between Young-onset and Late-onset Dementia. *Alzheimer Dis. Assoc. Disord.* **Publish Ahead of Print**,.
[54] Liu J, Abdin E, Vaingankar JA, Shafie SB, Jeyagurunathan A, Shahwan S, Magadi H, Ng LL, Chong SA, Subramaniam M (2017) The relationship among unawareness of memory impairment, depression, and dementia in older adults with memory impairment in Singapore. *Psychogeriatr. Off. J. Jpn. Psychogeriatr. Soc.*
[55] Yoon B, Shim YS, Hong YJ, Choi SH, Park HK, Park SA, Jeong JH, Yoon SJ, Yang D-W (2017) Anosognosia and Its Relation to Psychiatric Symptoms in Early-Onset Alzheimer Disease. *J. Geriatr. Psychiatry Neurol.* **30**, 170–177.
[56] Conde-Sala JL, Turró-Garriga O, Piñán-Hernández S, Portellano-Ortiz C, Viñas-Diez V, Gascón-Bayarri J, Reñé-Ramírez R (2016) Effects of anosognosia and neuropsychiatric symptoms on the quality of life of patients with Alzheimer's disease: a 24-month follow-up study. *Int. J. Geriatr. Psychiatry* **31**, 109–119.
[57] Rankin KP, Baldwin E, Pace-Savitsky C, Kramer JH, Miller BL (2005) Self awareness and personality change in dementia. *J. Neurol. Neurosurg. Psychiatry* **76**, 632–639.
[58] *Loi n° 2002-2 du 2 janvier 2002 rénovant l'action sociale et médico-sociale*.
[59] Johnston B, Narayanasamy M (2016) Exploring psychosocial interventions for people with dementia that enhance personhood and relate to legacy- an integrative review. *BMC Geriatr.* **16**, 77.
[60] Al-Aloucy MJ, Cotteret R, Thomas P, Volteau M, Benmaou I, Dalla Barba G (2011) Unawareness of memory impairment and behavioral abnormalities in patients with Alzheimer's disease: relation to professional health care burden. *J. Nutr. Health Aging* **15**, 356–360.

TABLES AND FIGURES

Table 1

The 22 items of the Awareness of Self and Disease Assessment (ASDA)

Objects	1.	Environment	Changes of the environment
	2.	Emotions	All new emotions
	3.	Body	Changes in sensations and physical abilities
	4.	Communication	Difficulties with verbal treatment information and verbalization
	5.	Autonomy	Difficulties during activities of daily living
	6.	Identity changes	Personality / mental / social status changes
	7.	Loss of cognitive abilities	Difficulties in concentration and location in space and time
	8.	Memory	Difficulties in learning and remembering information
	9.	Disease	Awareness of being a person with Alzheimer's disease
Mechanisms	1.	Observation of the environment	Awareness of changes with environment observation
	2.	Perception of the looks of others	Awareness of changes in the look / discourses / actions of others
	3.	Comparison between the past and the present	Awareness of differences in physical and psychological state and loss of independence and autonomy
	4.	Metacognition	Discourse on changes during a meta-representation / self-analysis
	5.	Confrontation of difficulties	Awareness of changes by observation of decreased physical and psychological abilities
Modes of expression	1.	Denial	Opposition, denial of changes and/or causes
	2.	Bewilderment	Expression of doubts/hesitations about daily life and the future
	3.	Attribution	Expression of changes with a causal attribution
	4.	Description	Expression of changes with a self-description
	5.	Judgment	Expression of changes with a self-assessment
	6.	Recognize the need for help	Expression of changes in recognizing the need for help during activities of daily living.
	7.	Use of coping strategies	Expression of changes by using coping strategies
	8.	Confirmation of the disease	Expression of changes by recognizing Alzheimer's disease

Table 2

Summary of the data

Item	Investigator 1		Investigator 2					
	% of missing values	Spearman correlations between T1 and T2	% of missing values	Spearman correlations between T1 and T2	Rater variance	ICC consistency	ICC agreement	Kappa
M1	2.7	.76**	12.5	.80**	-.00	.79	.79***	.08
M2	19.6	.69**	34.8	.79**	.17	.74	.70**	.50**
M3	2.7	.50**	12.5	.75**	-.00	.67	.67**	.08
M4	1.8	.55**	12.5	.58**	-.00	.77	.77***	.23*
M5	5.4	.42*	14.3	.65**	-.00	.71	.71**	.21*
O1	3.6	.62**	12.5	.58**	-.00	.73	.74**	.18
O2	2.7	.65**	12.5	.67**	-.00	.59	.59*	.08
O3	17.9	.59**	17.9	.87**	.01	.57	.57*	.09
O4	42.9	.32	47.3	.76**	.32	.32	.25	.30*
O5	33	.72**	36.6	.70**	-.00	.69	.70**	.61**
O6	4.5	.58**	11.6	.61**	.00	.65	.65**	.05
O7	15.2	.37*	30.4	.36*	.04	.59	.58*	.39*
O8	1.8	.56**	11.6	.62**	.06	.83	.81***	.11
O9	11.6	.73**	24.1	.71**	.00	.85	.85***	.53**
E1	0.9	.73**	10.7	.80**	.00	.66	.66**	-.02
E2	24.1	.61**	29.5	.69**	.07	.63	.60*	.33*
E3	17.9	.59**	42	.40*	.01	.60	.59*	.46**
E4	27.7	.29	25.9	.27*	-.00	.58	.58*	.50**
E5	2.7	.69**	10.7	.84**	-.00	.73	.73**	-.04
E6	28.6	.59**	34.8	.83**	.00	.60	.60*	.49**
E7	42.4	.13	45.5	.17	.03	.41	.40*	.52**
E8	17	.69**	34.8	.71**	-.00	.85	.85***	.55**

*Notes: * p < .05; ** p < .001*

ICC:
**Fair agreement >.40*
***Good agreement > .60*
****Excellent agreement > .75*
Cohen's kappa:
**Low agreement >.21*
***Mild agreement > .41*
****Strong agreement > .61*

Table 3

Cronbach’s alpha and correlation summary

		Investigator 1	**Investigator 2**		
ASDA category	**Number of items**	**Cronbach’s alpha**	**Cronbach’s alpha**	**r(MMSE)**	**r(AGE)**
ASDA	22	.93	.91	.27	.05
Mechanisms	5	.87	.86	.34*	.07
Objects	9	.81	.77	.22	-.06
Modes of expression	8	.87	.82	.25	-.01

Notes: * $p < .05$; ** $p < .001$