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Awareness of Self and Disease Assessment: Development and Validation of a Subjective Measure in People with Alzheimer's Disease

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

24 **Abstract:**

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

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

34 **Methods:** The new assessment tool consists of a semi-structured interview and ratings of 22
35 items divided into three categories. As part of our observational study, we assessed a sample of
36 28 PwAD who participated in four interviews (one every two weeks).

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

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

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

43 INTRODUCTION

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

55

56 *Assessing awareness through a system of reference*

57 *Discrepancies between the ratings of informants and PwAD*

58 A preliminary approach, which is the most common method in basic research [5],
59 considers discrepancies between informants’ and PwAD’s ratings of the disease or newly
60 perceived difficulties [6] (e.g., the Anosognosia Questionnaire-Dementia [7–9]; Assessment
61 Scale of Psychosocial Impact of the Diagnosis of Dementia [10]). The informant may be a
62 caregiver [11–14] or a clinician [15,16]. This approach considers many objects, such as
63 functional abilities [17], cognitive functions [18–21], health [14], autonomy [17,22,23], and
64 emotional and social functioning [24]. This first paradigm (i.e., discrepancies between
65 informants’ and PwAD’s ratings) provides a broad understanding of awareness levels in AD.
66 This method considers caregiver feedback (in a nursing home or at home) but has some

67 limitations. For instance, caregivers may deny the existence or lack knowledge of the disease.
68 Additionally, clinicians may overestimate the deficits of PwAD [16]. Some factors may
69 influence related assessments [25], such as relationships, time spent with PwAD, psychological
70 state [26], and knowledge of the disease [16]. The prediction-performance paradigm was
71 proposed to address these limitations.

72

73 ***Prediction-performance discrepancies***

74 Another type of assessment of the awareness of disease has been presented [3] in which
75 discrepancies between the predictions of PwAD and their performance on an objective task are
76 examined (e.g., the Multidimensional Isomorphic Simple Awareness Assessment
77 (MISAwareness) [27,28]; the Memory Awareness Rating Scale (MARS) [29]; the MARS-
78 Adjusted [30]). This prediction-performance paradigm is considered “*experimentally more*
79 *correct*” because it avoids all subjective and emotional biases [31], although it also has
80 limitations. For instance, differences may exist between the actual task and mental
81 representations. Moreover, most tasks are cognitive and specifically assess memory
82 performance [6,32]. Although the MISAwareness was developed to avoid these limitations
83 [27], the paradigm still focuses on cognitive functions without considering daily life activities.

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

87

88 ***From assessing awareness with an implicit system of reference toward the subjective*** 89 ***experiences of PwAD***

90 Clinical ratings are used in assessments based on PwAD's responses [6] (obtained with
91 a questionnaire, a semi-structured interview [35,36] or observation [37,38]). These clinical
92 ratings have good psychometric properties and seem to be convenient for care in nursing homes.
93 Moreover, such assessments can address items ranging from cognitive function to self-
94 perception. The first validated assessment was the Clinical Insight Rating [39]. Gil et al. (2001)
95 [40] suggested an assessment with a broader perspective on awareness, ranging from awareness
96 of the disease to awareness of self, which consists of 14 questions regarding general
97 information, emotions, relationships and abilities. This assessment includes awareness of self,
98 and this clinician rating considers the experiences of PwAD. Nevertheless, this type of method
99 has limitations. The information required to determine the level of awareness is obtained from
100 clinical appointments, which are framed by pathological guidelines. Consequently, an impaired
101 level of awareness is considered a symptom. PwAD are defined only as "Aware" or "Unaware"
102 according to their scores. To summarize, clinician ratings, which more closely reflect PwAD's
103 experiences, constitute an implicit system of reference: knowledge of the disease and
104 generalization of its evolution. Such ratings do not fully consider PwAD's discourse and their
105 daily experiences to understand their levels of awareness.

106 One purpose of person-centered approaches is to optimally reflect the subjective
107 experiences of PwAD that we regard as "*a return to the things themselves*" [41]. From this
108 perspective on subjective experiences, Johannessen, Engedal, Haugen, Dourado, and Thorsen
109 (2018) and Emery Trindade, Santos, Lacerda, Johannessen and Dourado (2018) [1,2] showed
110 that PwAD are still able to talk about their experiences with the disease. Thus, the consideration
111 of how PwAD live with the disease and perceive themselves seems helpful for determining
112 their awareness of the disease. To study PwAD's experiences and how they make sense of their
113 situation, Billiet et al. (2009) [3] adopted a phenomenological approach and focused on
114 PwAD's dialogue to model the process of awareness of the disease. With this grounded theory

115 approach, they observed an intertwined relationship between awareness of the disease and
116 awareness of self. The authors identified a comprehensive model organized into three
117 categories: objects, mechanisms and modes of expression. The objects represent the basis of
118 changes and new information perceived by PwAD (e.g., the environment, emotions, the body,
119 communication, autonomy, identity changes, loss of cognitive abilities and the disease). The
120 mechanisms are the processes of awareness (e.g., observation of the environment, perception
121 of the look of others, comparison between the past and the present, metacognition and
122 confrontation with difficulties). The modes of expression are how PwAD express their
123 awareness of the disease and/or self (e.g., denial, bewilderment, attribution, description,
124 judgment, recognition of the need for help, the use of coping strategies and confirmation of the
125 disease). In this category, awareness is considered using only verbal reports that can reflect
126 explicit awareness [42]. These initial approaches demonstrate the possibility of considering
127 PwAD's subjective experiences in awareness assessments.

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

136

137 **METHODS**

138 *Design*

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

143

144 ***Participants***

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

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

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

163

164 *Measure*

165 *Awareness of Self and Disease Assessment (ASDA)*

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

182 Subsequently, each interview was transcribed and rated. In detail, Billiet et al. (2009)
183 [3] proposed a theoretical approach to disease experience composed of three categories. To
184 assess awareness based on the interview, our scale followed these categories. Each semi-
185 structured interview was rated with objects, mechanisms and modes of expression. The
186 assessment tool was composed of 22 items: nine for the objects, five for the mechanisms and
187 eight for the modes of expression (Table 1). Each mechanism and mode of expression item was

188 rated on a 6-point Likert scale (1: “Minimally present”, 2:”Slightly present”, 3: “Mildly
189 present”, 4: “Moderately present”, 5: “Strongly present” and 6:“Extremely present”). Each
190 object item was rated on a 6-point Likert scale (1: “Strong unawareness”, 2: “Mild
191 unawareness”, 3: “Slight unawareness”, 4: “Slight awareness, 5: “Mild awareness” and 6:
192 “Strong awareness”). When an item was not evoked during the course of the interview, it was
193 noted as “Not Assessed”. A higher rating was associated with a higher level of awareness. No
194 cut-off score was applied to the ratings; the ASDA provides “a profile of awareness” (i.e., a
195 map of awareness) for each person with AD.

196 **[Table 1 here]**

197

198 *Data analysis*

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

206

207 **RESULTS**

208 *Preliminary analysis*

209 *Missing values*

210 The ASDA is a subjective measure based only on what PwAD were able to say.
211 Consequently, this method resulted in missing values. All ASDA items had a minimum of one

212 missing value (0.9% of rating items) and a maximum of 53 missing values (47.3% of rating
213 items) (Table 2). The strong presence of missing values (> 30%) for some items (O4:
214 Communication, O5: Autonomy, O7: Loss of cognitive abilities, E6: Recognize the need for
215 help, E7: Use of coping strategies and E8: Confirmation of the disease) introduces clinical
216 consequences about the inter- and intravariabilities of awareness for PwAD in nursing homes.
217 For this study, missing values influenced the quality of the analysis. To address the loss of
218 information, we used the “FactoMineR” and “MissMDA” packages to impute data.

219 **[Table 2 here]**
220

221 ***Internal consistency***

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

227 **[Table 3 here]**
228

229 ***Test-retest reliability***

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

238

239 ***Interrater reliability (ICC and Cohen's kappa)***

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

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

257

258 ***Correlations (Spearman correlations with age and MMSE score)***

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

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

266

267 **DISCUSSION**

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

275 The ASDA is based on grounded theory and PwAD’s comments about their daily lives with
276 the disease. This new rating system is based on clinical investigations, which allow close
277 representations of PwAD’s experiences. In this study, we observed that PwAD could self-report
278 their daily lives and confirmed the possibility and the need to consider subjectivity during care
279 [45–50]. Moreover, the assessment of awareness with the ASDA provided information about
280 the broader personal daily experiences of PwAD from their perspective. The ASDA extends
281 beyond disease symptoms by investigating several aspects of the respondents’ daily lives (e.g.,
282 mood and relationships).

283 The ASDA satisfies the social policy of implementing a person-centered approach with
284 good psychometric properties (internal consistency, test-retest reliability and interrater
285 reliability) for PwAD in an institution. We provided initial statistical information regarding the
286 feasibility of the ASDA and observed good internal consistency for all items and for each
287 category. Although the ASDA is based on a grounded approach using the discourses of PwAD

288 instead of theoretical definitions, it revealed common processes of awareness in each person.
289 For the most part, the ASDA also had good interrater reliability and test-retest reliability. These
290 two psychometric indicators suggest that the ASDA is not far removed from the processes of
291 awareness as experienced by each PwAD regardless of the investigator or temporality. With
292 regard to interrater reliability, the analyses were influenced by the methodology. Although the
293 reliability of the level of awareness was good, there was disagreement between the investigators
294 regarding the absence/presence of items during the interviews. This discrepancy may be
295 explained by the accessibility of information about the participants. Whereas one investigator
296 had full information (he/she met the participant four times, met health professionals, and had
297 information about care in the institution), the other investigator had only the transcriptions and
298 audio recordings. With this material, the second investigator could not appreciate all the
299 information that was available to the first investigator, which led to differences in ratings. This
300 bias highlights the importance of the relationship created between clinicians and PwAD and the
301 accessibility of other types of information (e.g., nonverbal behaviors, communication with
302 health professionals and information on care in an institution) in the assessment of awareness.
303 A future study could measure this bias by providing the same information to each investigator
304 (e.g., transcriptions and audio or video recordings).

305 Considering the characteristics of the sample, the level of awareness determined by the
306 ASDA is not associated with psychosocial factors such as age. This absence of an association
307 can be explained by coping strategies developed by both younger and older participants with
308 aging (e.g., to minimize their abilities and to anticipate and adjust to changes) [51]. Similarly,
309 the level of awareness is not associated with the cognitive deficit assessed by the MMSE, except
310 for the mechanisms assessed by investigator 1. These results are inconsistent with those of other
311 studies [52,53]. These differences in the findings can be explained by the type of methodology
312 used to assess awareness. Previous studies mainly assessed awareness through a system of

313 reference with a greater emphasis on cognitive functioning than our phenomenological
314 approach. Future research should explore this methodological influence.

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

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

338 In this study, we used a dataset composed of 112 scores from 28 participants who were each
339 interviewed four times. We used this dataset without taking into account repeated assessments
340 except for test-retest reliability. This choice was the consequence of variability in the
341 occurrence of particular themes. For each participant, we could not rate all items of the ASDA
342 in one interview. Therefore, we could note the absence of items in the rating. The lack of items
343 in the rating does not reflect unawareness but rather reflects an absence in the discourse during
344 the assessment. This temporal dependency could be induced by individual (e.g., cognitive
345 impairment, personality, fatigue), environmental (e.g., adapted, stimulating) and/or social
346 factors (e.g., relationship with the investigator). Despite this influence on the precision of the
347 statistical analysis, we obtained clinical information. First, there are inter- and intraindividual
348 variabilities of awareness over time. Second, more than one interview seems necessary to
349 address all the processes of awareness in research and in practice. A more detailed analysis of
350 the different clusters obtained and the level of temporal fluctuation of awareness could help to
351 enhance the personalization of care in nursing homes. In France, for example, upon entry to a
352 nursing home, each PwAD, with the help of health professionals, establishes a “*life project*”
353 [58]. This project, which is regularly revised, represents guidelines for care and activities in the
354 institution and depends on cognitive impairments, autonomy, and self-preferences and their
355 evolution. There is no assessment of awareness in these indicators, although Rice, Howard, &
356 Huntley (2019) [4] argued for the need to understand the perspective of PwAD to improve the
357 quality of care. The ASDA could easily be incorporated into these protocols because the ASDA
358 can be conducted by all care staff (e.g., psychologists, doctors, nurses), who only need to
359 understand the interview and rating procedures. For practicing professionals, the accessibility
360 of the ASDA procedure would provide a better understanding of the disease experience of
361 PwAD according to their level of awareness. This would address the urgency of understanding
362 the subjective experience of PwAD in care [4] and “*acknowledging the person behind the*

363 *patient*” [59]. Going beyond this main advantage of the personalization of care, a better
364 understanding of awareness could also produce benefits such as reducing professionals’ stress
365 during care [37,60].

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

372

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555 **TABLES AND FIGURES**

556

557 **Table 1**

558 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

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Table 2
Summary of the data

Item	Investigator 1		Investigator 2		Rater variance	ICC consistency	ICC agreement	Kappa
	% of missing values	Spearman correlations between T1 and T2	% of missing values	Spearman correlations between T1 and T2				
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**

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

564 ICC:
565 *Fair agreement > .40
566 **Good agreement > .60
567 ***Excellent agreement > .75
568 Cohen's kappa:
569 *Low agreement > .21
570 **Mild agreement > .41
571 ***Strong agreement > .61
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Table 3
Cronbach's alpha and correlation summary

ASDA category	Number of items	Investigator 1		Investigator 2	
		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

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