

ORIGINAL ARTICLE

Assessment of the information provided by the medical specialist on Alzheimer's disease and that retained by the patient caregivers[☆]

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KEYWORDS

Alzheimer's disease;
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Abstract

Introduction: There is evidence of insufficient communication abilities by medical specialists as well as of the limited retentive capacities of patients with Alzheimer's disease (AD) and their caregivers. The main reasons for this include the personal limitations of the physician, as well as external, emotional and social-cultural factors associated with the patients and their caregivers.

The aim of this study is to compare the clinical information on AD provided by the physicians and that perceived by caregivers and to assess factors associated with differences in perception. **Patients and methods:** We carried out an observational national multicentre study based on questionnaires assessing the information provided by the physician and that retained by the caregiver for 17 items of information. The study involved 61 researchers and included a total of 679 patients who met the selection criteria. We evaluated the factors associated with the difference in perception of the information that was transmitted.

Results: Participating caregivers had a mean age of 57.2 ± 14.8 years, with an average care time of 27.6 ± 28.0 months. Approximately half (50.9%) were children of the AD patient and most lived in the same household (64.9%). Caregivers assigned significantly higher ratings to information on concept of disease, aetiology, pathogenesis, dosage and treatment recommendations and adherence, while doctors assigned significantly higher ratings to information related to demystification and correcting preconceived notions, possible complications, adverse events and/or iatrogenesis, family associations, and emotional/psychological support to caregivers ($P < .05$). Concordance between the information provided and that received was classified between poor and weak (inter-rater agreement ≤ 0.27). The degree of disease progression using the Global Deterioration Scale (GDS) was a factor significantly associated with professional-carer information discrepancy ($P = .002$).

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PALABRAS CLAVE

Enfermedad de Alzheimer;
Cuidador;
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Transmisión

Conclusions: Many areas of information showed large differences in perception between physicians and caregivers of AD patients, which highlights the need to improve the communication process in order to achieve higher quality.

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Evaluación de la información suministrada por el médico especialista sobre la enfermedad de Alzheimer y de la retención lograda por los cuidadores del enfermo

Resumen

Introducción: Existen evidencias de la insuficiente capacidad informativa por parte de los especialistas médicos, así como de las dificultades retentivas de los pacientes con enfermedad de Alzheimer (EA) y de sus cuidadores. Entre las diversas causas figuran tanto las limitaciones personales del profesional como los determinantes externos, emocionales y socioculturales del paciente y de su cuidador.

Contrastar la información clínica proporcionada por los médicos sobre la EA y la percibida por los cuidadores y evaluar los factores asociados a las diferencias de percepción.

Pacientes y métodos: Se llevó a cabo un estudio observacional, multicéntrico y nacional mediante cuestionarios que evalúan la información suministrada por el médico y la retenida por el paciente en 17 aspectos informativos. Participaron 61 investigadores que incluyeron a un total de 679 pacientes que cumplían los criterios de selección. Se evaluaron los factores asociados a la diferencia de percepción sobre la información transmitida.

Resultados: Los cuidadores participantes tenían una media de $57,2 \pm 14,8$ años, habiendo dedicado un tiempo medio como cuidadores de $27,6 \pm 28,0$ meses, y siendo el 50,9% hijos del paciente que mayoritariamente vivían en el mismo domicilio (64,9%). Los cuidadores valoraron significativamente mejor la información recibida sobre: concepto de la enfermedad, aspectos etiopatogénicos, posología y recomendaciones sobre el tratamiento y adherencia terapéutica, mientras que los médicos consideraron significativamente mejor la información referente a desmitificación y corrección de concepciones previas, posibles complicaciones, riesgos, efectos adversos y/o yatrogenia, asociaciones de familiares, y ayuda emocional/psicológica a cuidadores ($p < 0,05$). La concordancia en la información suministrada y la recibida fue entre pobre y débil ($Kappa \leq 0,27$). El grado de evolución de la enfermedad (escala GDS) fue un factor significativamente asociado con la discordancia profesional-cuidador ($p = 0,002$).

Conclusiones: Se apreciaron diferencias de percepción entre médicos y cuidadores de pacientes con EA para numerosos aspectos informativos, evidenciando la necesidad de mejorar el proceso comunicativo para optimizar su calidad.

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Introduction

As life expectancies increase in developed countries, Alzheimer's disease (AD) is becoming the leading public health problem associated with the ageing population. In Spain, it is estimated that AD has a prevalence of 4.3% and an incidence of 9.5 cases per 1000 individuals per year.^{1,2} When care is provided by family members living with the patient, the family environment is affected by the stress, unease, and workload associated with the disease.³

Cholinesterase inhibitors have been shown to be specific and useful, and they are therefore used as a first-line treatment, especially during early and middle stages. Several studies have shown that anti-dementia drugs improve or stabilise cognitive, behavioural, and functional disorders linked to AD. They also delay symptom onset and institutionalisation, reduce mortality rate, decrease caregiver burden, and lower healthcare spending. Moreover, they have been shown to modify the clinical course of the disease^{4–8} by halting its progression for periods of up to 4 years.⁹ The use of anti-dementia drugs in clinical daily practice is still

limited,¹⁰ and treatment adherence has a tendency to gradually decrease, especially when other treatments are being used concomitantly.¹¹ These factors have a negative impact on treatment continuity, which is necessary in order to slow the progression of cognitive decline.^{12,13} According to some studies, 30% of patients undergoing treatment discontinue it during the first 60 days,¹⁴ and 14% of the patients who continue treatment for 180 days pass through periods in which treatment is interrupted for as long as 6 weeks.¹⁵

Therapeutic compliance in AD largely depends on the patient's caregiver, the information available to that caregiver, his trust in the doctor and his expectations, and his solutions for overcoming the constant challenges of managing the disease. In this context, a patient-focused care approach aims to include the family and the caregiver in decision-making that affects the patient. The caregiver's personal preferences should be considered when choosing among different treatments.

In this participatory approach to healthcare, the caregiver needs high-quality information that is easy to understand and adapted to fit his or her needs. It should

include an explanation of the disease, its natural course, and different available treatment options so that the caregiver may make independent and responsible decisions. In many cases, information provided to caregivers has a decisive effect on quality of care, and it is unfairly overlooked in spite of its effect on treatment compliance, patient and caregiver quality of life, and perceived satisfaction with healthcare. Some professionals provide information to patients spontaneously and without prior analysis, often using too many technical terms and allowing their own values to create a bias. As a result, caregivers may perceive the information as excessively cryptic, even though doctors feel that it has been presented properly.

Leaving other more specific communication deficiencies aside, there are several external factors contributing to information being insufficient. They include the patient's and the caregiver's cultural and intellectual levels, language barriers, conditions during the visit, factors affecting the doctor–patient relationship, the caregiver's emotional response to the course of the disease, etc. Therefore, studying and analysing the differences between doctors' impressions (transmitted information) and AD patient caregivers' impressions (retained information) may provide objective data to help neurologists reflect on the effectiveness and impact of their messages to the caregiver when diagnosing and treating AD patients.

The main objective of this study is to analyse how effective the neurologist, psychiatrist or geriatrician treating AD patients is at providing information. To this end, we describe differences between the information about the disease and its treatment as intentionally presented by the professional and the information as it is understood by the caregiver. This approach should permit us to evaluate the factors that are usually associated with differences in the way that doctors and caregivers perceive medical information being imparted. It may also identify information on AD that is difficult for caregivers to understand, and areas in which the caregiver's judgment, attitude, or care may need improvement.

Patients and methods

The current study was carried out by gathering written questionnaires with similar content that were administered simultaneously to doctors and caregivers of AD patients. We then evaluated information provided by the doctor and that retained by the caregiver by using a total of 17 well-defined items of information (Appendix B). Informal caregivers of AD patients were included in the study during a six-month recruiting period, using a consecutive sampling method in neurology, psychiatry, and geriatric medicine departments at different Spanish public health centres providing diagnosis, follow-up, and treatment for AD patients. The criteria employed for AD diagnosis were elaborated by the National Institute of Neurological and Communicative Disorders and the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA).¹⁶

Inclusion criteria for the study were as follows: patients diagnosed with AD without sex or age restrictions, and accompanied by their caregivers during a routine or

follow-up consultation. Specialist researchers were directly responsible for monitoring patients and providing information to caregivers. All selected patients are typically accompanied by their caregivers during specialist visits, and both patients and caregivers were required to sign an informed consent form.

Following the standard procedure, we selected patients of either sex who had been diagnosed with AD, were accompanied by their respective caregivers, and who had a diagnostic or follow-up appointment with the specialist. Researchers were required to participate directly in the patient's clinical monitoring and in providing information to the caregiver. As stated above, each patient and caregiver had to sign an appropriate informed consent form in order to be included. Caregiver-patient pairs were excluded if caregivers were unable to respond to the study questionnaire due to their educational level or a language barrier.

Two questionnaires were used for every caregiver–patient pair meeting inclusion criteria: one for the medical specialist and the other for the caregiver. Items on the questionnaires are listed below. Immediately after the diagnostic or follow-up consultation with the AD patient, the specialist filled in a questionnaire with 2 different sections. The first was a general section requesting his or her professional opinion about the doctor's role in informing the patient or caregiver (completed only once), and the second section requested a professional opinion about how well he or she had provided information to the caregiver during the diagnostic or follow-up consultation. This second section included the AD patient's medical profile and treatment plan and the survey on the applicability of the information presented to caregivers about the disease and its treatment. After the recruitment visit, the caregiver was interviewed by auxiliary staff members. Meanwhile, caregivers completed their questionnaires, which also contained 2 sections. The first section recorded the caregiver's sociodemographic profile and psychological state, and the second section evaluated the applicability of the information about the disease and its treatment which was presented to the caregiver during the consultation.

The second part of the questionnaire, completed by both researchers and caregivers, included the same 17 well-defined items formulated so as to assess the information presented, the information retained, and differences in perception between the 2 parties. These items refer to the following aspects: (1) concept of the disease, (2) debunking misinformation, (3) aetiopathogenesis, (4) natural history and prognosis of AD, (5) complications and risk situations, (6) genetic and heritable risks, (7) drugs and treatment alternatives, (8) expected treatment responses, (9) risks and adverse effects, (10) drug interactions, (11) treatment perspectives, (12) treatment dosages and recommendations, (13) adherence and risks associated with non-compliance with treatment, (14) anticipated benefits of complementary therapies, (15) social health resources and assistance, (16) family/caregiver associations, and (17) emotional and psychological support.

In order to describe potential differences of opinion between specialists and caregivers regarding each item of information, we calculated for each question the frequency of responses on a scale of 1 to 5 (where 1 indicates "very detailed information" and 5 indicates "very little/no

information'') for both the specialist and the caregiver groups. We calculated the average score assigned by each of the groups, in addition to the mean difference between the scores assigned by each group, for each item on the questionnaire. The statistical significance of any differences between the scores provided by each group was determined by performing a contrast hypothesis test for ordinal scales with paired data (Wilcoxon matched pairs/signed ranks test). The level of significance was established at .05.

We calculated Cohen's kappa coefficient and its 95% confidence interval¹⁷ as a corrected overall measure of inter-rater agreement for how doctors and caregivers assess information. Both of these groups were considered to be judges assessing the same action (the presentation of information during a clinical consultation). We used the Fleiss–Cohen (quadratic) weights method to calculate the relative importance of disagreements.¹⁸ The Bland–Altman method was used to interpret the coefficient (a value of 1 indicates perfect agreement and 0 indicates that the agreement is no better than one obtained by chance).¹⁹ All statistical analyses were performed using SAS software, version 9.1 (SAS Institute Inc., Cary, NC).

Results

Characteristics of the researchers

The study included 61 specialist researchers with a mean age ($\pm$ SD) of 45.9 ± 8.7 years; 62.3% were men. The mean time practising as specialists was 16.6 ± 9.5 years. The most common specialty was neurology (78.7%), followed by geriatric medicine (11.5%) and psychiatry (4.9%). More than half of the professionals (52.6%) provided care through the public system; the most common types of centres were general hospitals (67.2%) and outpatient specialty centres (41.0%). Clinical care was mainly provided by general neurology units (55.7%) and dementia specialist units (29.5%).

Sociodemographic and clinical description of AD patients

We recruited a total of 679 patients who met all selection criteria. Women accounted for 67.2% of the total and mean age was 77.5 ± 7.0 years. The average amount of time elapsed since the patients were diagnosed was 3.4 ± 2.2 years and their mean MMSE score was 18.1 ± 4.2 . Table 1A includes all of the demographic and clinical data.

Sociodemographic and clinical description of caregivers

The caregivers of AD patients included in the study had a mean age of 57.2 ± 14.8 years; mean period of time spent taking care of the patient was 27.6 ± 28.0 months. We observed that most of the caregivers lived in the same household as the patient (64.9%) and that most were family members (93.6%).

Table 1B includes additional sociodemographic and clinical information describing the caregivers. It should be

Table 1 Sociodemographic and clinical data of the patient (A) and the caregiver (B).

A)	
Patient	
<i>Sex (female), n (%)</i>	456 (67.2)
<i>Age (years), mean $\pm$ SD</i>	77.5 ± 7.0
<i>Progression timeline for AD (years), mean $\pm$ SD</i>	3.4 ± 2.2
<i>Score on MMSE, mean $\pm$ SD</i>	18.1 ± 4.2
<i>Stage of progression on GDS, n (%)</i>	
GDS-1, no cognitive decline	2 (0.3)
GDS-2, very mild cognitive decline	13 (2.0)
GDS-3, mild cognitive decline	101 (15.2)
GDS-4, moderate cognitive decline	316 (47.6)
GDS-5, moderately severe cognitive decline	206 (31.0)
GDS-6, severe cognitive decline	24 (3.6)
GDS-7, very severe cognitive decline	7 (0.3)
B)	
Caregiver	
<i>Sex (female), n (%)</i>	518 (76.3)
<i>Age (years), mean $\pm$ SD</i>	57.2 ± 14.8
<i>Time spent caring for the patient (months), mean $\pm$ SD</i>	27.6 ± 28.0
<i>Relationship to the patient, n (%)</i>	
Spouse	225 (33.4)
Son/daughter	343 (50.9)
Other family member	63 (9.3)
Professional caregiver	30 (4.5)
Others	13 (1.9)
<i>Type of domicile, n (%)</i>	
Caregiver lives in same household	437 (64.9)
Caregiver does not live in same household (day care)	197 (29.3)
Caregiver does not share the same household (night care)	19 (2.8)
Others	20 (3.0)
<i>Educational level, n (%)</i>	
No schooling/illiterate	14 (2.1)
Can read and write	84 (12.4)
Completed primary school	253 (37.5)
Completed secondary school	179 (26.5)
Introductory university studies	81 (12.0)
Advanced university studies	64 (9.5)
<i>HADS scale, mean $\pm$ SD</i>	
Anxiety subscale	6.8 ± 4.3
Depression subscale	5.8 ± 4.4
HADS questionnaire, n (%)	
<i>Anxiety subscale</i>	
No anxiety	405 (59.6)
Possible case of anxiety	145 (21.4)
Probable case of anxiety	129 (19.0)
<i>Depression subscale</i>	
No depression	453 (66.7)
Possible case of depression	130 (19.1)
Probable case of depression	96 (14.1)

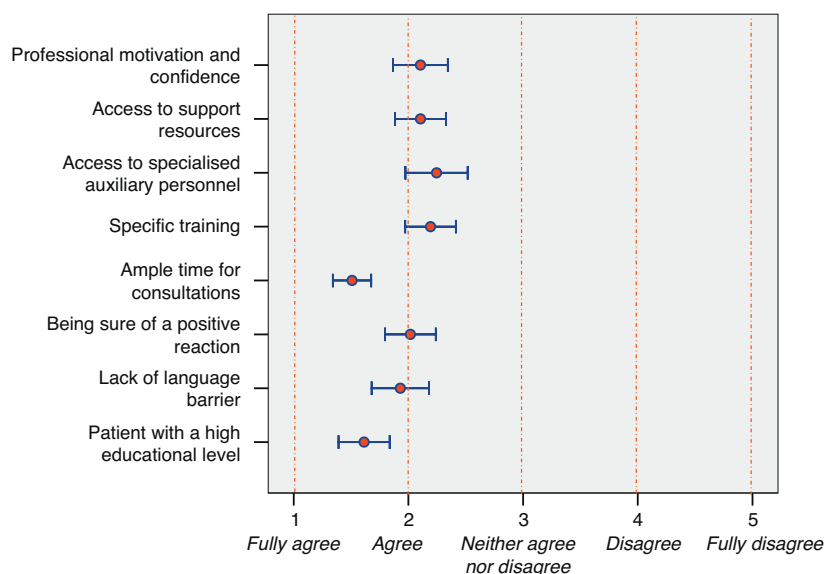


Figure 1 Medical specialists' opinion on factors that could potentially facilitate the task of providing information to caregivers of AD patients. The mean and 95% CI are shown for scores.

noted that 40.4% of the caregivers tested as likely or possible anxiety sufferers. Depression was also prevalent among caregivers, with 33.2% being possible or probable depression sufferers.

Researchers' and caregivers' general opinion on information provided during the consultation

Researchers listed factors that could potentially facilitate the task of presenting information to caregivers of AD patients. The importance of having enough time during the visit and the educational level of the patient were ranked as the most important factors in the process of providing information. Other important factors listed were absence of language barriers and being sure that information will be received in a positive way. These results are included in Fig. 1.

The analysis of caregivers' opinions regarding their need for information on AD revealed that almost a quarter of the caregivers had important questions that remained unanswered after the doctor had finished presenting information (Fig. 2A). Moreover, in nearly 30% of the cases, the caregiver considered that the information he or she had received was useful, but insufficient (Fig. 2B).

Disagreement between doctors and caregivers about the information provided/received

We analysed the 17 items on the questionnaire regarding information provided and received. Items were scored on a scale from 1 to 5 (from more detailed to more limited information). We calculated the means of scores assigned by each of the groups (doctors and caregivers) and identified any significant differences between the 2 groups (Table 2). Fig. 3 is a graph displaying the differences observed between scores given by doctors and by caregivers given to the information provided.

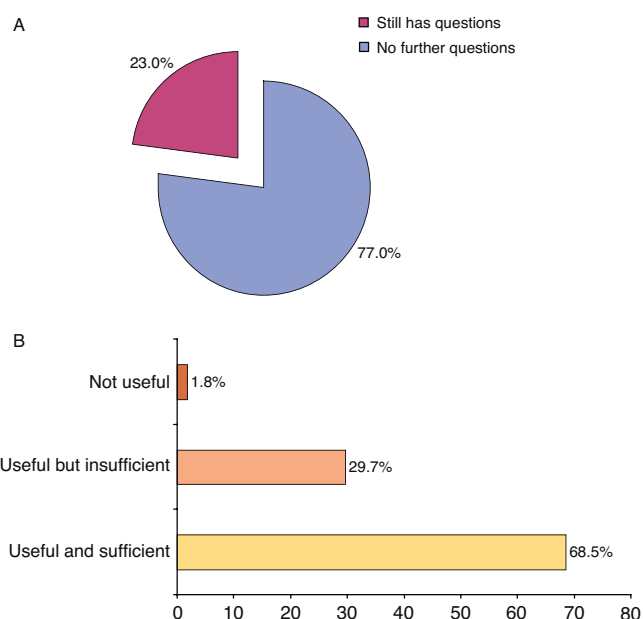


Figure 2 Assimilation of information by caregivers: (A) caregivers who still have relevant questions after hearing medical information and (B) caregivers' perception of how important the information received is to the patient's care.

Caregivers gave significantly better ratings to information on the concept of the disease, its aetiopathogenesis, drug dosages, and recommendations regarding treatment and treatment adherence ($P < .05$). On the contrary, medical specialists gave significantly better ratings to aspects such as debunking myths and correcting preconceived notions; possible complications, risks, adverse effects, and/or iatrogenesis; information about family associations; and emotional and psychological support for caregivers ($P < .05$).

Table 2 Evaluation of the different opinions of doctors and caregivers about information provided/received, and agreement between groups regarding evaluations.

Items	Quantity/quality of the information provided regarding...	Doctors (mean) ^a	Caregivers (mean) ^a	<i>P</i> ^b	Kappa	Concordance
1	Concept of the disease	2.3	2.1*	.001	0.23	Weak
2	Debunking myths and correcting preconceived notions	2.6*	2.9	.001	0.19	Poor
3	Aetiopathogenesis of the disease	3.1	2.8*	.001	0.13	Poor
4	Natural history of the disease and patient's prognosis (expected clinical progression, new symptoms, etc.)	2.4	2.4	0.055	0.23	Weak
5	Potential complications and risk situations (request for medical assistance, emergency medical attention, etc.)	2.5*	2.7	.001	0.26	Weak
6	Genetic and heritable risks, possibility of genetic diagnosis, etc.	3.2	3.1	0.294	0.23	Weak
7	Current drugs and treatment alternatives	2.3	2.3	0.181	0.22	Weak
8	Expected treatment responses, treatment effectiveness, duration, etc.	2.3	2.3	0.469	0.24	Weak
9	Risks/adverse effects/iatrogenesis	2.4*	2.6	.001	0.16	Poor
10	Potential drug interactions	2.7*	2.9	.001	0.21	Weak
11	New therapeutic perspectives	2.9	3.0	0.179	0.21	Weak
12	Dosage and recommendations for the prescribed treatment (periodicity, diet, dysphagia, refusal, etc.)	2.1	2.0*	0.038	0.24	Weak
13	Importance of treatment adherence and risks associated with treatment non-compliance	2.3	1.9*	.001	0.20	Poor
14	Expected benefits of complementary treatment (physiotherapy, speech therapy, occupational therapy, cognitive stimulation, etc.)	2.5	2.6	0.088	0.20	Poor
15	Information about the potential social health resources and assistance	2.7	2.8	0.294	0.21	Weak
16	Information about family/caregiver associations	2.9*	3.0	0.033	0.27	Weak
17	Information about emotional and psychological support for caregivers	3.0*	3.1	0.026	0.23	Weak

^a Mean calculated from the scores provided by each group (doctors and caregivers) according to the following scale: 1 = "very detailed", 2 = "complete", 3 = "basic", 4 = "superficial", 5 = "little or none".

^b The statistical significance of any differences between ratings provided by the 2 groups was determined using a Wilcoxon signed-rank test for matched pairs.

* Items rated more favourably by doctors or by caregivers are shown in bold where the differences between provided information and received information are significant ($P < .05$).

The qualitative assessment of agreement between doctors and caregivers on the subject of information was analysed by calculating the Kappa coefficient for each item of information in the study (a value of 1 indicates perfect agreement and 0 indicates that agreement is no better than might occur by chance). Overall, concordance between doctors and caregivers for the quality/quantity of the information received was weak ($Kappa \leq 0.27$) (Table 2). Nevertheless, concordance was clearly poor for some items, such as aetiopathogenesis, risks and adverse effects, debunking misconceptions, treatment adherence, and benefits of complementary treatments.

Factors associated with differing perceptions of information

In order to identify factors that could contribute to differences of opinion between professionals and caregivers regarding the information provided and that retained, we

formulated 17 new derived variables (qualitative and binomial), all permitting dichotomous classification of each item according to the difference between doctors' and caregivers' scores; each variable corresponds to one of the items of information under study. These derived variables were divided into two groups: "undervalued by the caregiver" when the caregiver's score for the transmitted information was less favourable than the doctor's (caregiver's score on the original scale is higher than the doctor's score), and "not undervalued by the caregiver" when the caregiver's score for the transmitted information was more favourable than the doctor's (caregiver's score on the original scale was the equal to or lower than the doctor's score).

With the help of the steps listed above, we calculated the percentage of disagreement for variables in the category "undervalued by the caregiver". These percentage scores were named "doctor-caregiver disagreement", and were expressed on a scale from 0 to 1 (where 0 indicates no disagreement and 1 indicates maximum disagreement). The mean value in this study was 0.29, indicating a considerable degree of disagreement.

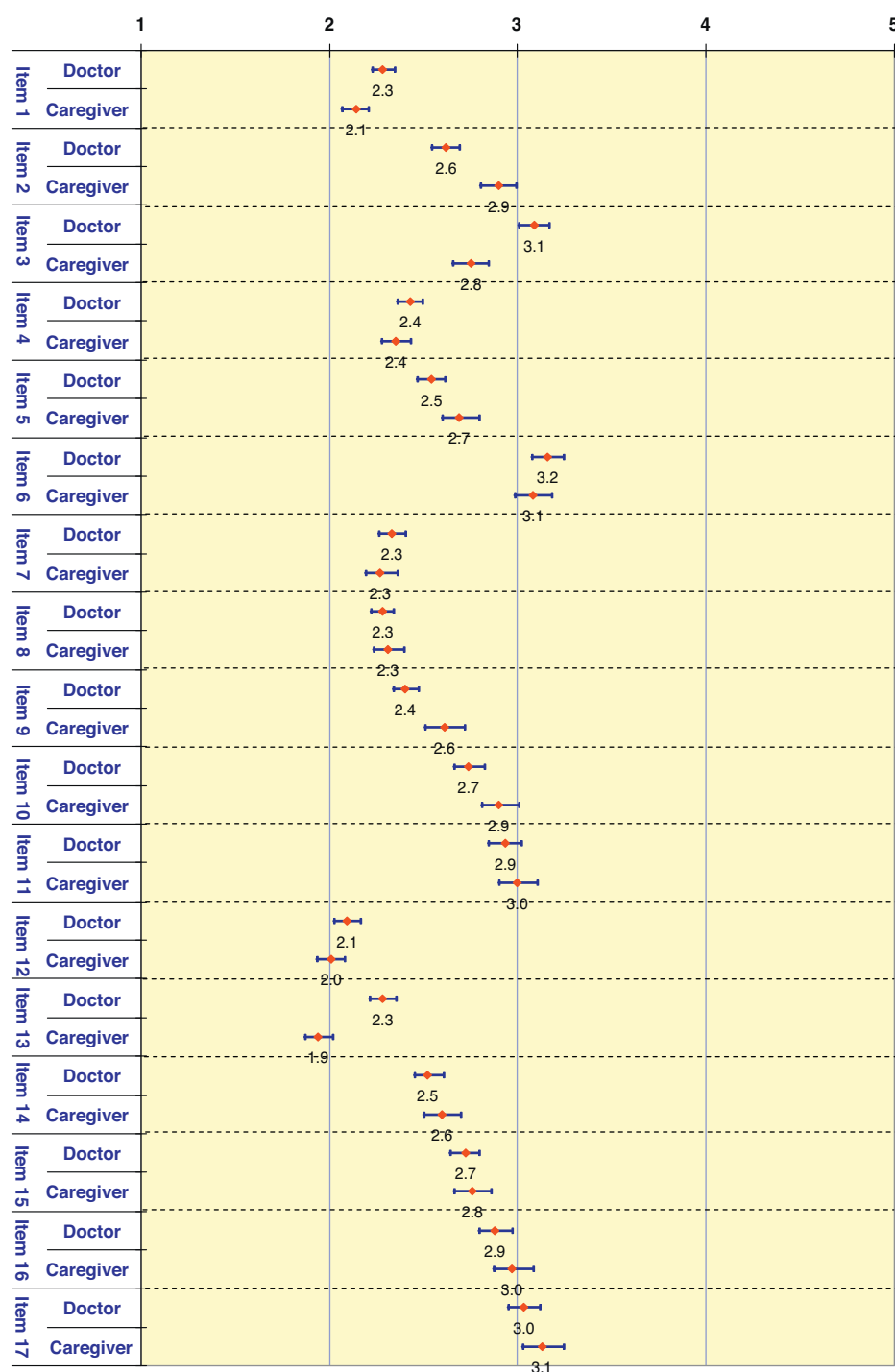


Figure 3 Mean differences between doctor and caregiver scores regarding information provided during the consultation. The mean and 95% CI are shown for scores. Assessed items: (1) concept of the disease, (2) debunking misinformation, (3) aetiopathogenesis, (4) natural history and prognosis of AD, (5) complications and risk situations, (6) genetic and heritable risks, (7) drugs and treatment alternatives, (8) expected treatment responses, (9) risks and adverse effects, (10) drug interactions, (11) treatment perspectives, (12) dosage and treatment recommendations, (13) adherence and risks associated with non-compliance with treatment, (14) anticipated benefits of complementary therapies, (15) social health resources and assistance, (16) family/caregiver associations, and (17) emotional and psychological support.

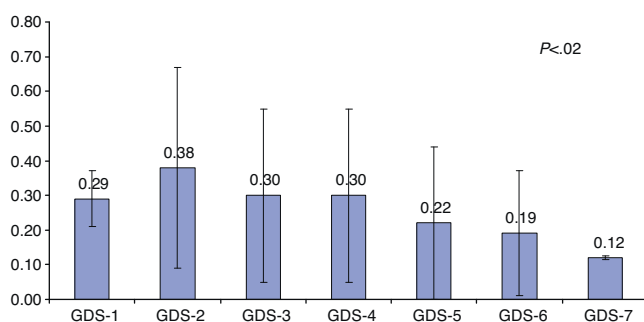


Figure 4 Stage of disease progression (GDS/Reisberg scale) and disagreement between doctors and caregivers regarding provided and received information.

Lastly, we identified any potential links between doctor–caregiver disagreement and characteristics of the caregiver’s profile (age, sex, educational level, emotional state, time spent caring for patient, personal relationship and living arrangement with the patient) or of the patient’s profile (age, sex, disease progression timeline, GDS (Reisberg) scale stage, score on the MMSE). The most significant result we obtained was that stage of progression (GDS scale) was the sole factor associated with a greater discrepancy between how doctors and caregivers perceived the information that had been provided/retained ($P = .002$) (Fig. 4).

Discussion

The results of this study show that there is a significant difference in the way doctors and AD patient caregivers perceive the information which the doctor presents and that which the caregiver assimilates. The main purpose of the initial analysis included in this study was to compare clinical information presented by AD specialists with the information understood and retained by their patients’ caregivers. With this purpose in mind, we aimed to identify the main factors associated with the differences in how information is perceived by doctors and caregivers in order to propose ways to improve communication in the process of caring for patients with Alzheimer’s disease.

Prior studies have uncovered differences in how information about illnesses such as Alzheimer’s disease is perceived. However, up to now, most of this evidence has been obtained from largely descriptive studies³ that to a certain extent lack a methodology for systematic analysis and are undertaken in order to establish general clinical guidelines for treating patients.^{20–22}

For the first time in Spain, our results allow us to describe the types and categories of information which medical specialists provide and which are most likely to be perceived differently by professionals and AD patients/caregivers. These results provided a more in-depth view of the reasons why caregivers are frequently unable to retain useful instructions intended to promote patient stability and a more favourable course of the disease.

Overall, our study shows that medical specialists need to have more time for consultations with patients. It also reports that the sociocultural characteristics of patients and

caregivers (language, educational level, etc.) may hamper their understanding of the information the doctors present. These factors are very well known, not only in the field of AD management, but also in most of the illnesses treated in neurology consultations and specialty centres.²³ On the other hand, our study confirms prior results by Kendall et al.²⁴: caregivers of AD patients frequently perceive that the information provided to them does not answer certain important questions. They feel that they do not have enough information, even if they do appreciate any efforts made to keep them informed.

Our study differs from other current studies in that it refers to specific and well-defined areas of information transmitted to caregivers and patients. It lists areas of information that need improvement in order to improve communications between medical specialists and caregivers. This is especially true in the context of a serious illness like Alzheimer’s disease, which imposes significant physical, economic and emotional burdens on the caregiver.²⁵

Our study shows that caregivers of AD patients gave a positive rating to information they received regarding the concept of the disease, treatment recommendations, and treatment dosage. In clear contrast to the above, medical specialists were especially satisfied with the information they presented to debunk preconceived notions and warn caregivers about risk situations, and information on family associations, support groups, and similar resources. This obvious disparity in the subjective assessments of the information provided and that received (with poor objective values for concordance) highlights some of the communication problems present in neurology departments when following up on patients with AD. This disparity may also be related to a specific lack associated with treating common dementia problems and providing effective assistance to these patients’ caregivers: there is considerable need for better education and social support if caregivers are to overcome the emotional distress associated with AD, and this need is well-understood in primary care centres.²⁶

Leaving aside the discrepancies identified by the analytical tools used in our study, identifying those factors directly associated with the level of disagreement was problematic. We were only able to link the stage of AD progression to differences in perception of the information presented and that retained. Therefore, for more advanced stages of AD, we observed increased agreement between medical specialists and caregivers regarding information. This association could be related to the benefits of early diagnosis which caregivers report; early diagnosis may facilitate the assimilation, understanding and processing of information about the disease. In addition, it may be helpful in planning future care,²⁷ in spite of the increasing responsibility and burden assumed by the caregiver as the physical and mental state of the AD patient worsens.³

Such a finding calls attention to the importance of a properly integrated approach to providing information on AD. This vision takes into account the three basic pillars of the care process: the medical specialist, the patient, and the caregiver.²⁸ Successfully presenting optimised and correctly selected information that can be retained by the caregiver would result in more efficient care from both the patient and the caregiver perspectives; this in turn would

significantly lower the risk of the patient being admitted to a residence²⁹ and lower the social and health costs of caring for the patient.^{30,31}

In conclusion, we should highlight that this study revealed significant discrepancies in the way the 2 groups (medical specialists and caregivers of AD patients) perceive information. For 10 of the 17 areas of information that were assessed, the information presented by the doctors and received by the caregivers was rated differently. The results of the study show that the doctor-patient communication process must be improved in order to optimise the quality and quantity of the information that caregivers effectively receive and retain. In this way, the excellent service they provide to our society will become increasingly efficient and sustainable.

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Conflicts of interest

Dr. J.L. Molinuevo has received fees as a consultant for the following pharmaceutical companies: Pfizer, Ellan Pharmaceuticals, Roche, Bristol-Myers Squibb, Novartis, Lundbeck, Janssen-Cilag, General Electric, Bayer, and Innogenetics. Dr. B. Hernández is employed by Novartis Farmacéutica, S.A.

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Appendix A. TRACE Study Working Group

TRACE Working Group: Valero Pérez Camo (Unidad de Salud Mental Delicias, Zaragoza), María Concepción Ortiz Domingo (Hospital San Juan de Dios, Zaragoza), Paloma González García (Hospital San José, Teruel), Teresa Calatayud Noguera (Hospital Universitario Central de Asturias, Oviedo), Juan Antonio Gil López (Clínica de Neuropsiquiatría, Gijón), José Gutiérrez Rodríguez (Sociosanitaria Larrañaga, Avilés), Eloy Rodríguez Rodríguez (Marqués de Valdecilla, Santander), Miguel Goñi Imizcoz (Hospital Divino Vallés, Burgos), Javier Ruiz Martínez (Hospital Donostia, San Sebastián), Jorge Aguirre Inchusta (Clínica Padre Menni, Pamplona), Lourdes San Martín Ganuza (La Vaguada, Pamplona), Agustín Urrutia Sanzberro (Centro Hospitalario Benito Menni, Elizondo), José Luis Sánchez Menoyo (Aita Menni Ospitalea, Bilbao), Javier Ruiz Ojeda, Bilbao), José Marey López (Centro Hospital Universitario A Coruña), Juan Carlos Porven Díaz (Hospital San José, Lugo), María Teresa Olcoz Chiva (Hospital Meixoeiro, Vigo), Margarita Vinuela Beneitez, Instituto Carbonell, Palma de Mallorca), Ana María Pujol Nuez

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Feria Vilar (Hospital General Albacete), Inmaculada Abellán Miralles (Hospital San Vicente de Raspeig, Alicante), Jordi Alom Poveda (Hospital General de Elche), Juan Marín Muñoz (Unidad de Demencias Arrixaca, Murcia), Luís Carles Dies

(Centro Carles Egea, Murcia), Luís Miguel Cabello Rodríguez (Hospital Naval, Cartagena), Antonio Salvador Aliaga (Hospital Clínico de Valencia), Rosario Muñoz Lacalle (Unidad de Salud Mental Sueca, Alzira).

Appendix B.

CUESTIONARIO GENERAL AL MÉDICO

Nota: Este formulario será contestado en una única ocasión por cada investigador, al iniciar su participación en el estudio.

a) Perfil profesional del investigador

Edad: (años)

Sexo: ☐ Hombre ☐ Mujer

Experiencia (años de ejercicio como especialista):(años)

Especialidad:

- ☐ Neurología
- ☐ Geriátrica
- ☐ Psiquiatría
- ☐ Otra, especificar:

Ámbito asistencial en el que trabaja: ☐ Público ☐ Privado ☐ Ambos

Tipo de centro de trabajo (indicar uno o varios):

- ☐ Hospital general
- ☐ Centro ambulatorio de especialidades
- ☐ Consulta individual
- ☐ Centro Geriátrico
- ☐ Centro especializado en demencia
- ☐ Consulta monográfica de demencia hospitalaria
- ☐ Otro, especificar:

Tipo de unidad en la que desempeña mayoritariamente su asistencia:

- ☐ Consulta de Neurología general
- ☐ Consulta de Geriátrica general
- ☐ Consulta de Psiquiatría general
- ☐ Consulta Monográfica de Demencia
- ☐ Unidad de Demencia (multiprofesional)
- ☐ Otra, especificar:

b) Opiniones generales del profesional sobre su papel como informador sanitario a los cuidadores de los pacientes con demencia

1. Evalúe la importancia que Vd. concede, en relación a su responsabilidad en la atención clínica (diagnóstico, tratamiento,...), a la tarea de informar al cuidador y/o paciente con demencia en su consulta:

- ☐ Mucho más importante que la atención clínica
- ☐ Más importante que la atención clínica
- ☐ Tan importante como la atención clínica
- ☐ Menos importante que la atención clínica
- ☐ Mucho menos importante que la atención clínica

2. ¿Quién debe llevar el peso principal de esta labor informativa al cuidador y/o paciente con EA? (si piensa que debe ser compartido, marque varios agentes):

- ☐ El especialista responsable del tratamiento
☐ Enfermeras del servicio especializado
☐ Médicos de Atención Primaria
☐ Enfermeras de Atención Primaria
☐ Otros profesionales sanitarios (psicólogos, neuropsicólogos,...)
☐ Otros agentes socio-sanitarios (trabajador social, voluntarios,...)
☐ Asociaciones de pacientes y familiares.
☐ Otros agentes (especificar)

3. ¿Qué tiempo medio dedica a la información de los cuidadores del paciente durante la visita de diagnóstico de la demencia?:

Dedicación media a la información por consulta diagnóstica..... minutos

Duración media de la consulta de diagnóstico..... minutos

4. ¿Qué tiempo medio dedica a la información de los cuidadores del paciente durante la visita de seguimiento de la demencia?:

Dedicación media a la información por consulta de seguimiento..... minutos

Duración media de la consulta de seguimiento minutos

5. ¿Cuál de los siguientes instrumentos considera útil para suministrar información al paciente? (Marque con una cruz todas las casillas que desee)

- ☐ Material escrito sobre la patología
☐ Acceso a páginas de Internet
☐ Realización de curso relación Médico Paciente
☐ Material educativo para pacientes de uso en consulta
☐ Tarjetón informativo para entrega al cuidador
☐ Otras, especificar cuáles

6. Indique, en su experiencia personal, si considera las circunstancias mostradas a continuación como factores dificultadores de su labor de información a los cuidadores de los pacientes con EA en su consulta diaria:

MARQUE "X" EN ÚNICA ÚNICA CASILLA POR FILA

Factores que dificultan la transmisión de información a cuidadores de pacientes EA	① Pleno acuerdo	② Acuerdo	③ Ni acuerdo, ni desacuerdo	④ Desacuerdo	⑤ Pleno desacuerdo
Bajo nivel cultural/educativo del paciente/ cuidador	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Dificultades idiomáticas	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Temor a la reacción psicológica negativa del paciente y/o cuidador	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Falta de tiempo en consulta / exceso de presión asistencial	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Falta de formación específica en habilidades de información al paciente.	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
No disponer de personal auxiliar específico para esta función	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
No disponer de materiales de ayuda para informar (folletos, libros, monografías, videos...)	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Desmotivación y desconfianza en el impacto de la información.	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Otros (indicar)	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo

7. Indique, en su experiencia personal, si considera que los siguientes factores facilitarían su labor de información a los cuidadores de los pacientes con EA en su consulta diaria:

MARQUE "X" EN ÚNICA ÚNICA CASILLA POR FILA

Factores que facilitan la transmisión de información a cuidadores de pacientes EA	① Pleno acuerdo	② Acuerdo	③ Ni acuerdo, ni desacuerdo	④ Desacuerdo	⑤ Pleno desacuerdo
Alto nivel cultural/educativo del paciente/ cuidador	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Ausencia de dificultades idiomáticas	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Confianza en la reacción psicológica positiva del paciente y/o cuidador	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Tiempo suficiente en consulta / presión asistencial ajustada a las necesidades de la consulta	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Formación específica en habilidades de información al paciente.	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Disponer de personal auxiliar específico para esta función	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Disponer de materiales de ayuda para informar (folletos, libros, monografías, videos...)	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Motivación del profesional y confianza en el impacto de la información.	Pleno acuerdo	Acuerdo	Ni acuerdo, ni desacuerdo	Desacuerdo	Pleno desacuerdo
Otros (indicar)	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna

CUESTIONARIO ESPECÍFICO AL MÉDICO SOBRE CADA PACIENTE RECLUTADO

“Opiniones profesionales sobre la labor informativa realizada a los pacientes/cuidadores de estudio”

Nota: De este cuestionario deberá contestar un ejemplar individual sobre su experiencia de atención a cada paciente reclutado.

1. Perfil clínico-terapéutico del paciente con EA reclutado sobre el que se va a opinar:

- Edad (años):
- Sexo: ☐ Hombre ☐ Mujer
- Tiempo de evolución de la EA (años):
- Fase evolutiva de la EA según la escala GDS: Global Deterioration Scale de Reisberg (ver anexo al final de este cuestionario).
 - ☐ GDS-1, ausencia de alteración cognitiva
 - ☐ GDS-2, disminución cognitiva muy leve
 - ☐ GDS-3, defecto cognitivo leve
 - ☐ GDS-4, defecto cognitivo moderado
 - ☐ GDS-5, defecto cognitivo moderado-grave
 - ☐ GDS-6, defecto cognitivo grave
 - ☐ GDS-7, defecto cognitivo muy grave
- Puntuación actual del paciente en el MMSE: Mini Mental State Exam (ver anexo al final de este cuestionario):

..... puntos

2. Tiempo desde el diagnóstico de la enfermedad de Alzheimer

..... Años Meses

3. Criterio del especialista sobre la adecuación de la información sanitaria transmitida sobre la enfermedad y su tratamiento al paciente/cuidador en este caso concreto.

¿El paciente había expresado su voluntad de conocer su diagnóstico?

- ☐ SI
☐ No

¿El cuidador había expresado su voluntad de conocer el diagnóstico del paciente?

- ☐ SI
☐ No

¿Ha informado expresamente al cuidador de que el paciente a su cargo sufre una demencia de Alzheimer?

- ☐ SI
☐ No

¿Ha informado expresamente a este paciente de que sufre una demencia de Alzheimer?

- ☐ SI
☐ No

En cada ítem de la lista siguiente, elija una única opción de la escala de respuesta propuesta, representando lo mejor posible su opinión personal

Considerando las circunstancias reales de su consulta, de este paciente concreto y de su cuidador, por favor, valore la calidad / cantidad de información que Vd. ha podido suministrar al familiar / cuidador durante la / s consulta / s con este paciente concreto, sobre los siguientes aspectos de la enfermedad y su tratamiento...

MARQUE "X" EN ÚNICA ÚNICA CASILLA POR FILA

INFORMACIÓN SUMINISTRADA SOBRE ...	① Muy detallada	② Completa	③ Básica	④ Superficial	⑤ Escasa-Ninguna
Concepto de la enfermedad.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Desmitificación y corrección de concepciones previas erróneas.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Aspectos etiopatogénicos de la enfermedad.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Historia natural de la enfermedad y pronóstico del paciente (evolución clínica esperable, nuevos síntomas, ...).	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Posibles complicaciones y situaciones de alarma (solicitud de ayuda médica, asistencia a urgencias...).	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Riesgos heredo-familiares, posibilidades de diagnóstico genético, ...	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Alternativas fármaco-terapéuticas actuales.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Expectativas de respuesta terapéutica: efectividad, duración, ...	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna

Riesgos/efectos adversos/yatrogenia.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Posibles interacciones medicamentosas.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Nuevas perspectivas terapéuticas	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Posología y recomendaciones de uso del tratamiento prescrito (ritmo de ingesta, alimentación, disfagia, rechazo..)	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Importancia de la adherencia y riesgos del incumplimiento terapéutico.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Beneficios esperables del tratamiento complementario (fisioterapia, logoterapia, terapia ocupacional, estimulación cognitiva...).	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Información sobre posibles recursos y ayudas socio-sanitarias.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Información sobre asociaciones de familiares /cuidadores.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Información sobre ayuda emocional y psicológica dirigida a los cuidadores	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna

CUESTIONARIO ESPECÍFICO AL CUIDADOR DE CADA PACIENTE RECLUTADO

“Opiniones profesionales sobre la labor informativa realizada a los pacientes/cuidadores de estudio”

Nota: De este cuestionario deberá contestar cada cuidador un ejemplar individual sobre la información recibida con respecto a cada paciente reclutado. Este cuestionario debe ser administrado por el personal auxiliar de la consulta (D.U.E o psicólogo) en el espacio más breve posible a la salida del paciente y el cuidador de la consulta del profesional

1. Perfil del cuidador del paciente con Enfermedad de Alzheimer:

- Edad
- Sexo: ☐ Hombre ☐ Mujer
- Tiempo al cuidado del paciente: meses
- Relación con el paciente:
 - ☐ Cónyuge
 - ☐ Hijo/a
 - ☐ Otro familiar
 - ☐ Allegado (vecino, ...)
 - ☐ Servicio doméstico
 - ☐ Cuidador profesional (empleado)
 - ☐ Otro
- Tipo de convivencia con el paciente:
 - ☐ Vive en el mismo domicilio
 - ☐ No comparte domicilio (cuidado diurno)
 - ☐ No comparte domicilio (cuidado nocturno)
- Nivel de estudios:
 - ☐ Sin instrucción / analfabeto.
 - ☐ Lee y escribe
 - ☐ Primarios
 - ☐ Secundarios / bachiller
 - ☐ Universitarios grado medio
 - ☐ Universitarios superiores

- Estado psicológico del cuidador: Escala HADS (Escala Hospitalaria de Ansiedad y Depresión)

Esta prueba está dirigida a determinar cómo te has sentido en la última semana a pesar de que las preguntas están formuladas en presente. Debes elegir entre una de cuatro posibilidades con respecto a la pregunta realizada, rodeando con un círculo la respuesta elegida.

1. Me siento tenso o nervioso. (A)
 - (0) Nunca.
 - (1) A veces.
 - (2) Muchas veces.
 - (3) Todos los días.
2. Todavía disfruto con lo que antes me gustaba. (D)
 - (0) Como siempre.
 - (1) No lo bastante.
 - (2) Sólo un poco.
 - (3) Nada.
3. Tengo una sensación de miedo, como si algo horrible me fuera a suceder.
 - (0) Nada.
 - (1) Un poco, pero me preocupa.
 - (2) Si, pero no es muy fuerte.
 - (3) Definitivamente, y es muy fuerte.
4. Puedo reírme y ver el lado divertido de las cosas. (D)
 - (0) Al igual que siempre lo hice.
 - (1) No tanto ahora.
 - (2) Casi nunca.
 - (3) Nunca.
5. Tengo mi mente llena de preocupaciones. (A)
 - (0) Sólo en ocasiones.
 - (1) A veces, aunque no muy a menudo.
 - (2) Con bastante frecuencia.
 - (3) La mayoría de las veces.
6. Me siento alegre. (D)
 - (0) Casi siempre.
 - (1) A veces.
 - (2) No muy a menudo.
 - (3) Nunca.
7. Puedo estar sentado tranquilamente y sentirme relajado. (A)
 - (0) Siempre.
 - (1) Por lo general.
 - (2) No muy a menudo.
 - (3) Nunca.
8. Me siento como si cada día estuviera más lento. (D)
 - (0) Nunca.
 - (1) A veces.
 - (2) Muy a menudo.
 - (3) Por lo general en todo momento.
9. Tengo una sensación extraña, como de "aleteo" en el estómago. (A)
 - (0) Nunca.
 - (1) En ciertas ocasiones.
 - (2) Con bastante frecuencia.
 - (3) Muy a menudo.
10. He perdido interés por mi aspecto personal. (D)
 - (0) Me preocupo al igual que siempre.
 - (1) Podría tener un poco más cuidado.
 - (2) No me preocupo tanto como debiera.
 - (3) Totalmente.
11. Me siento inquieto, como si no pudiera parar de moverme. (A)
 - (0) Nada.
 - (1) No mucho.
 - (2) Bastante.
 - (3) Mucho.

12. Me siento optimista respecto al futuro. (D)
(0) Igual que siempre.
(1) Menos de lo que acostumbraba.
(2) Mucho menos de lo que acostumbraba.
(3) Nada.
13. Me asaltan sentimientos repentinos de pánico. (A)
(0) Nada.
(1) No muy a menudo.
(2) Bastante a menudo.
(3) Muy frecuente.
14. Me divierto con un buen libro, la radio o un programa de televisión. (D)
(0) A menudo.
(1) A veces.
(2) No muy a menudo.
(3) Rara vez.

2. Opiniones del cuidador sobre la información facilitada por su especialista:

¿Le han explicado exactamente cual es el diagnóstico del problema del paciente que tiene a su cargo?

- ☐ Demencia
☐ Enfermedad de Alzheimer
☐ Deterioro propio del envejecimiento
☐ Problemas de memoria
☐ Desconoce el diagnóstico
☐ Otras opciones (detallar)

.....

A continuación le pedimos que valore la información sobre la enfermedad de Alzheimer y el tratamiento que usted ha recibido durante la/s consulta/s médica/s con especialista que atiende al paciente a su cargo. Por favor, exprese libremente sus opiniones según lo que usted crea haber entendido a su médico durante la/s consulta/s. Cuando elija sus respuestas, considere si la información que ha recibido sobre cada uno de los aspectos que se recogen en la siguiente tabla le ha parecido suficiente y claramente comprensible.

MARQUE "X" EN ÚNICA ÚNICA CASILLA POR FILA

INFORMACIÓN SUMINISTRADA SOBRE ...	①	②	③	④	⑤
	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
¿Qué es la enfermedad que sufre el paciente?.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
¿Cuáles son las causas / origen de esta enfermedad?	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
¿La información ha cambiado alguna idea preconcebida o errónea sobre la enfermedad?.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Pronóstico del paciente: evolución esperable de la enfermedad (nuevos síntomas, evolución del trastorno,...).	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Posibles complicaciones y situaciones de alarma (solicitud de ayuda médica, asistencia a urgencias...).	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Riesgo de enfermedad en familiares y posibilidades de diagnóstico precoz.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Tratamientos disponibles en la actualidad para esta enfermedad.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Resultados esperables de los tratamientos (mejoría, duración del efecto,...).	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna

Riesgos y efectos indeseables de la medicación.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Posibles interacciones con otros medicamentos. Contraindicaciones.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Nuevas posibilidades terapéuticas en la enfermedad	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Recomendaciones de administración del medicamento aconsejado (horarios, comidas, dificultades para tragar, rechazo...)	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Importancia de administrar la medicación de forma continuada.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Posibles beneficios del tratamiento complementario (fisioterapia, logoterapia, terapia ocupacional, estimulación cognitiva...)	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Posibilidades de ayuda socio-sanitaria	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Información sobre asociaciones de familiares /cuidadores.	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna
Información sobre ayuda psicológica dirigida a los cuidadores	Muy detallada	Completa	Básica	Superficial	Escasa-Ninguna

3. Carencias informativas en el cuidador y resolución de dudas:

- Sobre los aspectos recogidos anteriormente u otros referidos a la enfermedad o su tratamiento, tras ser informado por el médico, ¿le quedaron dudas o preguntas importantes, no satisfechas?
☐ No ☐ SI
- En caso afirmativo, ¿ha tenido fácil acceso posterior a la resolución de esas dudas con un sanitario? ☐ No
☐ SI
- En caso afirmativo, ¿quien le aclaró sus dudas? (señale uno o varios):
 - ☐ Médico especialista
 - ☐ Enfermera del servicio especializado
 - ☐ Médico de Familia
 - ☐ Enfermera de Atención Primaria
 - ☐ Otro agente, especificar
- ¿Considera que la información recibida será útil para el cuidado de su paciente?

Muy útil y suficiente ☐ Útil pero insuficiente ☐ No ha sido útil ☐
- Indique de las siguientes opciones los instrumentos que considera más útiles y preferibles (hasta un máximo de tres) para recibir información sobre la enfermedad, su evolución y cuidados,...
 - ☐ Disponer de material impreso de uso en consulta (folletos informativos, carteles).
 - ☐ Disponer de fuentes informativas fiables en Internet
 - ☐ Disponer de material videográfico
 - ☐ Disponer de otros materiales impresos de entrega (libros, monografías,...)
 - ☐ Otros (indicar)

4. Opinión del cuidador sobre el impacto de la administración de la medicación antidemencia al paciente (si la encuesta se efectúa tras la primera visita diagnóstica, las cuestiones siguientes no proceden)

Si ya tiene experiencia en suministrar medicación anti-demencia del paciente a su cargo...

- ¿La administración de medicación antidemencia representa un motivo de estrés personal en el cuidado del paciente que atiende?
Si ☐ No ☐

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