

# Consequences of Anosognosia on the Cost of Caregivers' Care in Alzheimer's Disease

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## Abstract.

**Background:** Anosognosia is common in patients with Alzheimer's disease (AD) and it is frequently related to an increase in time of care demand.

**Objective:** The aim of the study was to examine the effect of anosognosia on the total costs of informal care in patients with AD.

**Methods:** This was a prospective longitudinal study with community-dwelling AD patients. Anosognosia, time of informal care, and the use of support services (e.g., day care centers) were recorded at baseline and after 24 months. The cost of informal caregiving was calculated as 'market price'.

**Results:** At baseline, the prevalence of anosognosia was 54.3% ( $n = 221$ ), and 43.9% were classified as mild-AD. The average time of care was 5 h/day  $\pm$  2.4 (IADL: 1.3 h/day  $\pm$  1.4 and BADL: 3.6 h/day  $\pm$  1.5). Thirty percent of the patients used home care services, and 25.1% attended a day care center. Patients with anosognosia received more time of care and were more likely to use support services than did their no-anosognosia peers, including institutionalization. The mean cost of support services was 490.4€/month (SD = 413.1€; range = 25–2,212.38€), while the overall cost of care (support services plus informal care) was 1,787€/month (SD = 972.4€), ranging from 834.1€ in mild-AD without anosognosia patients, to 2,424.8€ in severe-AD with incident anosognosia patients.

**Conclusions:** Anosognosia was associated with an increased number of hours of informal care, and a greater use of support services, regardless of the severity of the dementia, which lead to an increase of the total family-care costs.

**Keywords:** Alzheimer's disease, anosognosia, cost of illness, dementia, health care costs, longitudinal studies

## INTRODUCTION

The costs of dementia care are frequently divided into formal and informal costs. Informal costs refer

to the amount of unpaid informal caregiver's time spent on patient's care [1] and represents 40 to 80% of dementia costs, which range from US\$315 billion to US\$604 billion in western countries [2–5].

The cost of informal care is mainly determined by the place of residence of the patient. As much as 83% of the people with dementia want to stay in their own home, as published by the annual report 'Support, Stay, Save' of the Alzheimer's Society (UK) [6].

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40 Most patients with dementia are cared for at home,  
41 which causes an increase in informal costs, adding an  
42 economic burden on families instead of on healthcare  
43 systems [1].

44 Caring for a relative with dementia has a hard  
45 impact on the emotional, physical, and economical  
46 situation. The economic value of this impact has been  
47 estimated using the cost of professional caregivers as  
48 a basis (cost of formal care) or by providing a mone-  
49 tary value to the possible loss of opportunities due to  
50 the time spent as a caregiver [7, 8].

51 Previous studies related informal costs to the pro-  
52 gressive increase of the patient's dependency, to the  
53 severity of the dementia, and to the presence of  
54 behavioral and psychological symptoms of demen-  
55 tia (BPSD) [5, 9]. One of the BPSD that has been  
56 reported to increase the perceived caregiver's burden  
57 is anosognosia, the lack of disease awareness [10, 11].

58 The prevalence of anosognosia in AD patients is  
59 over 25%, and it is cognitive decline-related, with  
60 around 80% of the patients with severe AD having  
61 anosognosia [12]. Patients with anosognosia present  
62 more BPSD than patients with no anosognosia, such  
63 as delusions [13], disinhibition, and apathy [14].  
64 BPSD cause an increase of the burden, the distress,  
65 and the cost of care [15]. Besides, the quality of  
66 life perception and the efficiency of neurocognitive  
67 rehabilitation are negatively affected by the presence  
68 of anosognosia [16–17]. All these factors associ-  
69 ated with the presence of anosognosia, even when  
70 they may also appear in patients with mild cogni-  
71 tive impairment [18], have an effect on the impact  
72 of the informal care required by the patient. Further-  
73 more, patients with anosognosia are more likely to  
74 engage in risky behaviors, which increases the bur-  
75 den of the caregivers due to the need of increased  
76 supervision and control, which may even lead to early  
77 institutionalization [19]. Moreover, the presence of  
78 anosognosia has been linked to an increased sense  
79 of isolation, greater physical and emotional burden,  
80 and a patient-caregiver relationship characterized by  
81 greater dependency [20]. Overall, therefore, the pres-  
82 ence of anosognosia may be associated with greater  
83 care needs, either regarding the number of hours of  
84 care needed or the use of health and social support  
85 services.

86 To our knowledge, this is the first study to ana-  
87 lyze the impact of anosognosia on informal costs.  
88 Our hypothesis was that the presence of anosognosia  
89 may cause an increase in the cost of care due to the  
90 increased time of care, the increased use of resources,  
or to both.

## METHODS

### *Design and study population*

This was a longitudinal study involving a 24-month  
follow-up of a consecutive sample of outpatients seen  
at the Dementia Unit (Department of Neurology) of  
Bellvitge University Hospital (Hospitalet de Llobre-  
gat, Barcelona). They were all diagnosed as either AD  
according to the criteria of the Diagnostic and Statis-  
tical Manual of Mental Disorders [21] or probable  
AD according to the criteria of the National Institute  
of Neurological and Communicative Disorders and  
Stroke / Alzheimer's disease and Related Disorders  
Associations (NINCDS-ADRDA) [22]. The main  
caregiver was defined as the person with ongoing  
responsibility for helping the patient with activities  
of daily living (ADL). All the caregivers were rela-  
tives of the patient, mainly daughters/sons or spouses.  
Informed consent was obtained for all participants.  
Patients were excluded if they presented with vascular  
or traumatic events, alcohol or substance dependency  
or abuse, and if they had severe communication prob-  
lems or had a severity of Global Deterioration Scale  
(GDS) stage 7 [23] that prevented them from respond-  
ing adequately to the assessment questions. The study  
was approved by the hospital's Clinical Research  
Ethics Committee (ref. PR162/10).

### *Data collection*

A structured questionnaire designed ad hoc was  
used to gather information on the use of resources  
such as day care centers, home care services, resi-  
dential care, and memory-training programs, as well  
as on the time spent helping with both instrumental  
ADL (IADL) and basic ADL (BADL). The question-  
naire also allowed collecting sociodemographic data  
of both patients and caregivers.

The time of care was assessed using two items of  
the Resources Utilization in Dementia scale (RUD)  
[24], which were administered to the caregivers: "*On  
a typical care day during the last 30 days, how  
much time per day did you assist the patient with  
tasks such as toilet visits, eating, dressing, grooming,  
walking and bathing?*" as BADL, and "*On a typi-  
cal care day during the last 30 days, how much time  
per day did you assist the patient with tasks such  
as shopping, food preparation, housekeeping, laun-  
dry, transportation, taking medication and managing  
financial matters?*" as a question of IADL.

The cognitive assessment of the patients was based on the Mini-Mental State Exam (MMSE), a brief cognitive assessment tool with a score ranging from 0 to 30 (the lower the score the greater the cognitive deterioration) [25].

The functional assessment of the patient was based on the Disability Assessment for Dementia (DAD) [26]. The DAD provides a measure of basic and instrumental ADL and was administered to the main caregiver. It comprises 40 items and its total score ranges from 40 to 80 (the higher the score the greater the patient's functional ability).

The severity of dementia was classified according to the criteria of the GDS, a tool designed to determine the stage of a patient's dementia. GDS 4 corresponds to mild dementia, GDS 5 to moderate dementia, and GDS 6 to moderately severe dementia.

The presence of BPSD was evaluated by means of the Neuropsychiatric Inventory (NPI) [27], which comprises 12 subscales that assess the frequency and severity of 12 neuropsychiatric symptoms (or BPSD), based on information provided by caregivers. The score ranges from 0 to 144, and the higher the score the greater the frequency and severity of neuropsychiatric symptoms.

Finally, anosognosia was assessed using the Anosognosia Questionnaire-Dementia (AQ-D) [28], a tool that is administered both to the patient and the caregiver. It comprises 30 items assessing cognitive/functional deficits and changes in the patient's behavior, with each item being rated according to the frequency of occurrence, from 0 (never) to 3 (always). The total score ranges from 0 to 90. The degree of anosognosia is estimated on the basis of the difference between the patient and caregiver's scores. The cut-off for the presence of anosognosia was established at difference  $\geq 32$  points. We identified asymptomatic cases when anosognosia was not present in any evaluation, incident cases when patients without anosognosia at baseline developed it during the follow up, and persistent cases when anosognosia was present both at baseline and during the follow up.

### Procedure

Neurologists from the Dementia Unit selected eligible patients according to the inclusion criteria. The sample was recruited between January and December 2011 and the study finished on March 2014. The aims of the study were explained to all the participants in an introductory interview, and an informed consent

Table 1

Monthly cost of the health and social support services considered in the study

Service	Mean €/month
Memory-Training programs	25.00*
Day center**	
<i>Weekly</i>	336.72
<i>Daily</i>	617.72
Home care services†	
<i>Occasionally</i>	77.53
<i>Weekly</i>	232.60
<i>Daily</i>	387.70
Residential care**	1,595.06

\*approximate cost for 10 h/month; \*\*Data from the Catalan government for such services in 2010; †Price/hour established by Barcelona City Council for home care services in 2013; Occasionally = 1 day/week; Weekly = 3–4 days/week; Daily = 5–7 days/week.

was obtained from both patients and caregivers before proceeding. The patients and their caregivers were then interviewed separately by two clinical psychologists trained in the administration of the study protocol instruments.

The economical cost of time of care was evaluated as market price, thus attributing the cost per hour of private professionals [29]. The attribution of costs and the cost of using different health and social resources are shown in Table 1. The cost of day care centers and residential care was derived from the costs established by the Catalan government [30], the cost per hour for home care services was based on the figures set by the Barcelona City Council [31], and the cost of attending memory-training programs and day care centers was taken as the mean cost of 10 hours/month of such services in the area where the patient lived. The hourly cost of informal care was taken to be equivalent to the cost per hour of a geriatric nursing assistant providing help with BADL. The standard for costs per hour was obtained from the Catalan Office of National Statistics [32].

### Statistical analysis

Differences between missing cases and those that completed the follow-up were analyzed using either parametric or non-parametric tests according to the criteria of normality, for continuous variables, and with the Pearson chi-square test for categorical variables.

Longitudinal data were analyzed by means of generalized linear models (GLM), because some dependent variables were not normally distributed [33–34]. This approach enabled us to examine the

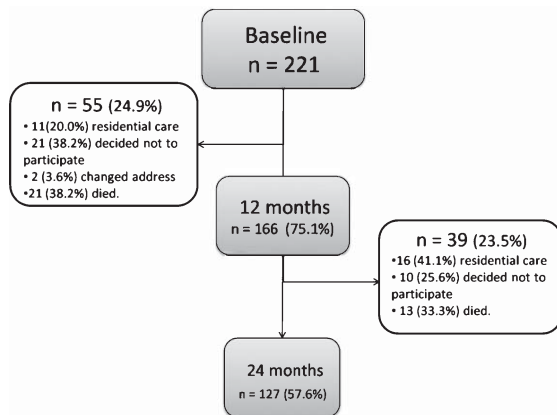


Fig. 1. Flowchart showing changes in the sample's characteristics over the 24-month period.

general effects of the independent variables (time, severity, anosognosia status), and the interaction between them (Time  $\times$  Severity  $\times$  Anosognosia), as well as the simple effects of differences between the groups. The dependent variables for each model were the number of care hours (total, instrumental and basic ADL) and the cost of care (hours and resources).

For hypothesis contrasts, the level of statistical significance was set at 0.05. All data processing and analysis was performed using IBM SPSS Statistics for Windows, version 20.0 (Armonk, NY: IBM Corp.).

## RESULTS

The baseline sample comprised 221 patients and their respective caregivers, of whom 75.1% completed the follow-up assessment at 12 months and 57.5% the assessment at 24 months. At baseline, only four families of those initially invited declined to participate. Lost cases ( $n=94$ ) were more impaired at baseline than were patients who completed the follow-up ( $n=127$ ); specifically, they had greater cognitive impairment (MMSE=17.2 versus 19.1;  $p=0.014$ ), poorer functional ability (DAD=54.7 versus 60.6;  $p<0.001$ ), a greater degree of anosognosia (AQ-D=38.9 versus 30.2;  $p=0.001$ ), and more neuropsychiatric symptoms (NPI=31.2 versus 20.9;  $p<0.001$ ). Fig. 1 shows the drop off reasons over the 24-month period.

### Sociodemographic and clinical data

The sociodemographic and clinical characteristics of the study participants at each visit are shown in

Table 2. The mean age of caregivers at baseline was 63.8 (SD=13.0), 151 (68.3%) were women, and 56 (25.3%) had fewer than five years of formal education. Spouses accounted for 54.7% of informal caregivers (54.8% women), while 40.7% were sons or daughters of the patient (77.0% women).

### Needs and use of services

The caregivers provided, on average, 5 h/day of informal care (SD=2.4; range=0–12), distributed across BADL (1.3 h/day; SD=1.4; range=0–6) and IADL (3.6 h/day; SD=1.4; range=0–6). Time of care was related to the dementia severity (GDS). Thus, the time requested by GDS4 patients was 2.6 h/day (SD=1.7), while for GDS6 patients it was 7.0 h/day (SD=1.8) ( $F=274.8$ ;  $df=2$ ;  $p<0.001$ ). The time of care showed a moderate correlation with BPDS ( $\rho=0.405$ ;  $p<0.001$ ) but when including the NPI score as an independent variable in the GLM, the relation with cost over 24 months was not significant ( $F=1.449$ ;  $df=487$ ;  $p=0.229$ ).

The resources used by the patients and their caregivers are described in Table 3. At the 24-month follow-up, 74.5% of cases used, at least once, the available health and social services. The proportion of patients using these resources did not change during the two-year study period: 68.8% at baseline, 74.7% at 12 months, and 66.1% at 24 months ( $\chi^2=4.6$ ;  $df=2$ ;  $p=0.101$ ). Across the 24 months of follow-up 4.7% of patients were institutionalized.

### Impact of anosognosia on the care received by patients

Anosognosia was observed in 54.3% of the patients at baseline. Over the follow-up period, 27.2% of the cases ( $n=140$ ) remained asymptomatic, 22.2% ( $n=114$ ) presented with anosognosia at either 12 or 24 months (patients without anosognosia at baseline who developed it during the follow up), and anosognosia persisted in 50.6% ( $n=260$ ) of the cases (anosognosia present at baseline and during the follow up). A request for help from the relatives and/or the use of services was registered in 82.9% of the cases with anosognosia versus 61.8% of those without anosognosia ( $\chi^2=28.9$ ;  $df=2$ ;  $p<0.001$ ).

From baseline onwards, patients with anosognosia required more hours of care than did their asymptomatic counterparts (Wald=37.1;  $df=2$ ;  $p<0.001$ ). During the follow-up period, asymptomatic cases were also less likely to use health and social

Table 2  
Clinical and sociodemographic data of patients

	Baseline <sup>1</sup> (n = 221)	12 months <sup>2</sup> (n = 166)	24 months <sup>3</sup> (n = 127)	Differences p
Age	77.8 (0.4)	78.6 (0.5)	79.0 (0.6)	0.276*
Women	140 (63.3)	104 (62.7)	82 (64.6)	0.944**
Education				0.864**
<Primary school	140 (63.3)	108 (65.1)	84 (66.1)	
≥Primary school	81 (36.7)	58 (34.9)	43 (33.9)	
GDS, n (%)				<0.001**
4	97 (43.9)	38 (22.9)	12 (9.4)	
5	78 (35.3)	67 (40.4)	40 (31.5)	
6	46 (20.8)	61 (36.7)	75 (59.1)	
MMSE, mean (SD)	18.3 (0.4)	16.3 (0.4) <sup>a</sup>	15.2 (0.5) <sup>b</sup>	<0.001*
DAD, mean (SD)	58.1 (0.7)	54.0 (0.8) <sup>a</sup>	50.0 (0.9) <sup>b,c</sup>	<0.001*
IADL	30.2 (0.4)	28.1 (0.4) <sup>a</sup>	26.3 (0.5) <sup>b,c</sup>	<0.001*
BADL	27.9 (0.3)	25.8 (0.4) <sup>a</sup>	23.6 (0.5) <sup>b,c</sup>	<0.001*
NPI, mean (SD)	25.3 (1.2)	24.4 (1.4)	28.6 (1.6)	<0.001*
AQ-D (>32), n (%)	120 (54.3)	106 (63.9)	84 (66.1)	0.049**
Factor 1	28.8 (1.0)	29.4 (1.3)	31.6 (1.7)	0.361*
Factor 2	5.1 (0.3)	4.9 (0.4)	4.7 (0.5)	0.696*
Difference	33.9 (1.2)	36.4 (1.4)	37.9 (1.6)	0.135*

\*\*Pearson  $\chi^2$  test for categorical variables. \*Generalized linear model, Wald  $\chi^2$ . Means, estimated marginal. SE, standard error. Significant with Bonferroni *post hoc* contrasts: <sup>a</sup>1–2, <sup>b</sup>1–3, <sup>c</sup>2–3. Fixed effects, time. Covariables, else: GDS, Global Deterioration Scale. MMSE, Mini Mental State Examination. DAD, Disability Assessment for Dementia. IADL, instrumental activities of daily living. BADL, basic activities of daily living, NPI, Neuropsychiatric Inventory. AQ-D, Anosognosia Questionnaire-Dementia (>32: Anosognosia); Factor 1, cognitive and functional. Factor 2, behavioral.

Table 3  
Frequency of use of different support services according to the presence or absence of anosognosia, stratified by assessment point

n (%)	Baseline			12 months			24 months		
	No anosognosia	Anosognosia	p	No anosognosia	Anosognosia	p	No anosognosia	Anosognosia	p
Memory-Training programs	15 (14.9)	10 (8.3)	0.128	14 (23.3)	16 (15.1)	0.185	6 (14.0)	12 (14.3)	0.959
Day center			0.029			0.045			0.616
No	83 (82.2)	81 (67.5)		52 (86.7)	75 (70.8)		33 (76.7)	61 (72.6)	
Weekly	10 (9.9)	16 (13.3)		0 (0.0)	4 (3.8)		0 (0.0)	0 (0.0)	
Daily	8 (7.9)	23 (19.2)		8 (13.3)	27 (25.5)		10 (23.3)	23 (27.4)	
Home care service			0.320			0.697			0.043
No	74 (73.3)	80 (66.7)		45 (75.0)	71 (67.0)		33 (76.7)	54 (64.3)	
Occasionally	6 (5.9)	5 (4.2)		4 (6.7)	7 (6.6)		0 (0.0)	10 (11.9)	
Weekly	13 (12.9)	16 (13.3)		16 (10)	16 (15.1)		7 (16.3)	8 (9.5)	
Daily	8 (7.9)	19 (15.8)		5 (8.3)	12 (11.3)		3 (7.0)	12 (14.3)	
Residential care	1 (1.0)	4 (3.3)	0.243	0 (0.0)	5 (4.7)	0.088	3 (7.0)	11 (13.1)	0.297
Alzheimer's Association	25 (24.8)	45 (37.5)	0.042	25 (41.7)	45 (42.5)	0.922	19 (44.2)	32 (38.1)	0.508
Use of resources	59 (58.4)	93 (77.5)	0.002	35 (58.3)	89 (84.0)	<0.001	32 (74.4)	75 (89.3)	0.030
GDS 4	36 (50.0)	19 (76.0)	0.024	14 (51.9)	10 (90.9)	0.024	5 (45.5)	1 (100)	0.296
GDS 5	18 (78.3)	39 (70.9)	0.504	17 (70.8)	30 (69.8)	0.927	12 (85.7)	19 (73.1)	0.361
GDS 6	5 (83.5)	35 (87.5)	0.777	4 (44.4)	49 (94.2)	<0.001	15 (83.3)	55 (96.5)	0.051

Pearson  $\chi^2$  test for categorical variables. GDS, Global Deterioration Scale. Occasionally = 1 day/week. Weekly = 2–4 days/week. Daily = 5–7 days/week. Alzheimer's Association, affiliation to the local Alzheimer's Association or similar.

300 services than patients with incident or persis-  
301 tent anosognosia ( $\chi^2 = 9.3$ ;  $df = 2$ ;  $p = 0.009$ ). The  
302 mean time dedicated by caregivers to help with  
303 the patient's BADL was 1.1 h/day for asymp-  
304 tomatic cases (SE = 0.1), 1.2 h/day for the incident  
305 group (SE = 0.1), and 1.4 h/day (SE = 0.1) for per-  
306 sistent cases; the corresponding figures for IADL  
307 were 3.2 h/day (SE = 0.1), 3.7 h/day (SE = 0.1), and

3.9 h/day (SE = 0.1), respectively. The presence of  
anosognosia increased the use of health and social  
services, including institutionalization ( $\chi^2 = 5.5$ ;  
 $df = 2$ ;  $p = 0.018$ ). Overall, resources were used by  
50.5% of the asymptomatic cases versus 66.8%  
of patients with anosognosia ( $\chi^2 = 13.6$ ;  $df = 2$ ;  
 $p < 0.001$ ). Alongside anosognosia, the severity of  
dementia was the other main factor associated with

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the use of resources: one or more resources were used by 53.7% of patients at GDS stage 4, by 56.8% of those at GDS 5, and by 69.2% of those at GDS 6 ( $\chi^2 = 9.6$ ;  $df = 2$ ;  $p = 0.008$ ) (Table 3).

The presence of anosognosia was associated with an increase in the time dedicated to the informal care of the patients, regardless of the dementia severity (Wald = 9.0;  $df = 2$ ;  $p = 0.011$ ). Figure 2 shows the number of hours dedicated per day to provide help with BADL and IADL, according to the severity of dementia and stratified by the patient's anosognosia status.

### Attribution of costs

Based on the attribution of cost per hour of care, the cost of informal care was 851.9€/month (SD = 546.2; range = 0–2,091.9€) for BADL and 544.7€/month (SD = 349.2; range = 0–1337.6€) for IADL. The cost of all support services was 490.4€/month (SD = 413.1; range = 25–2,212.38€); the cost of home care services was 259.3€/month (SD = 115.4; range = 77.5–378.7€), while it was 552.1€/month (SD = 119.0; range = 336.7–617.3€) for day center attendance. The total cost across the 24-month follow-up period was 1,787€/month (SD = 972.4), with the cost of informal care (caregiver hours) accounting for 83.4% of the total. The cost of support services was significantly higher at 24 months ( $F = 3.6$ ;  $df = 2$ ;  $p = 0.026$ ).

In the generalized linear model the total cost of care (support services plus caregiver hours) did not differ significantly between baseline, 12 months, and 24 months (Wald = 0.374;  $df = 2$ ;  $p = 0.829$ ), and neither was there an interaction effect (Time  $\times$  Severity of Dementia  $\times$  Anosognosia) on this total cost (Wald = 179.7;  $df = 15$ ;  $p = 0.279$ ). Therefore, the analysis of total cost was stratified only according to anosognosia status and to the severity of dementia (Wald = 11.1;  $df = 4$ ;  $p = 0.026$ ). However, a summary table showing the variable Time has been included as Supplementary Material (Supplementary Table 1). Table 4 shows that the lowest cost corresponded to asymptomatic cases (no anosognosia) at GDS stage 4 (834.0€/month), whereas the highest cost corresponded to cases with incident anosognosia and at GDS 6 (2,424.8€/month).

## DISCUSSION

The main purpose of this work was to describe the effect of anosognosia in the cost of care, using

the daily hours of care and the use of resources as cost-indicators.

The informal care provided by relatives is fundamental to AD patients' attention. Principal characteristics of AD, such as functional dependence and neuropsychiatric symptoms are the main factors related with an increase of the time of care. However, both the perceptions of caregiving stress and the positive aspects of caregiving are appraised through a cultural/ethnic lens [35], and whereas Caucasians generally place earlier the loved ones in care facilities [36], African Americans and Latinos tend to delay institutionalization [37]. Informal care is usually provided by close relatives, especially if one of these is a woman. In agreement with previous research, our results show that external support services still account for a relatively small proportion of the overall care that is provided (around 15% of the total cost).

However, although traditional roles and relationships persist within the provision of informal care in Spain, research suggests that caregivers are beginning to ask for different kinds of help from government agencies [1]. Whereas twenty years ago caregivers were most likely to request financial assistance in the form of a monthly caregiver allowance, the main demand nowadays is for home care services and greater training. These home care services would include the use of day care centers and the access to other kind of formal support, such as tele-care [38].

Several studies have reported specific data about the cost of formal and informal care to patients with dementia [39–41]. The factors that influence the cost of care can be classified in two groups: dementia-directly related factors and factors related to caregiver's burden. The first group encloses functional disability, anosognosia, and neuropsychiatric symptoms, among others [42]. In our analyses neuropsychiatric symptoms were not significant, which may be due to the fact that dementia severity is influenced-by the presence of neuropsychiatric symptoms. In another study, the NPI scores were barely related with an increment of the caregiving costs, and it was the dependence scale that largely explained the variance of the caregiving costs [43]. The second group is related with the caregiver burden perception. We previously reported an increase of the burden perception associated with anosognosia [20], and there is evidence that greater burden is related to a greater use of resources [44]. We did not include the burden in our study due to its strong relationship with anosognosia.

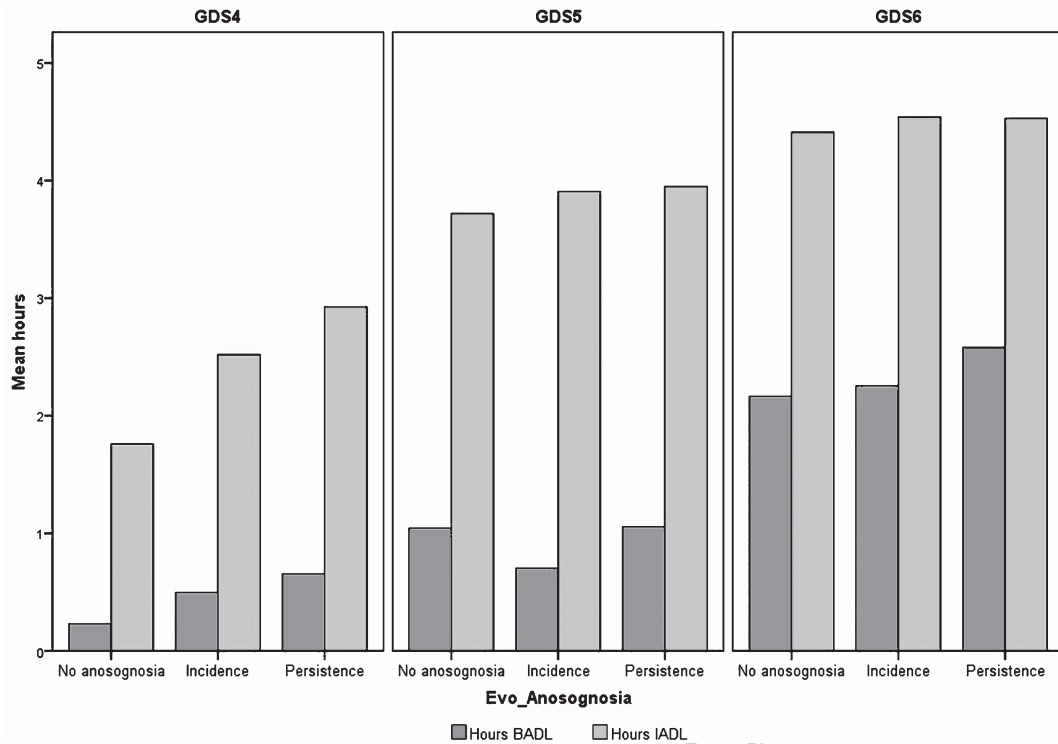


Fig. 2. Number of hours dedicated per day to helping with basic and instrumental ADL, according to the severity of dementia and stratified by the patient’s anosognosia status.

Table 4

Total combined monthly cost of informal care by family caregivers and external support services, stratified by severity of dementia and anosognosia status

TOTAL COST	GDS 4		GDS 5		GDS 6		Simple Effects $\chi^2$ ; (df); p
	n	Mean (SE)	n	Mean (SE)	n	Mean (SE)	
Total cost	147	1189.2 (72.4)	185	1815.0 (64.4) <sup>a</sup>	182	2243.9 (64.9) <sup>b,c</sup>	118.1; (2); <0.001
Anosognosia status							
1. No anosognosia	74	834.0 (101.2)	38	1,704.4 (138.1) <sup>a</sup>	28	2,099.5 (162.4) <sup>a,b</sup>	52.9; (2); <0.001
2. Incidence	41	1,324.8 (137.9) <sup>d</sup>	47	1,927.5 (124.1) <sup>a</sup>	26	2,424.8 (169.7) <sup>a,b</sup>	24.9; (2); <0.001
3. Persistence	32	1,715.1 (155.8) <sup>e</sup>	100	1,790.6 (87.7)	128	2,248.1 (75.2) <sup>b,c</sup>	19.2; (2); <0.001
Simple Effects: $\chi^2$ ; (df); p		25.7; (2); <0.001		1.5; (2); 0.472		1.9; (2); 0.373	

Model  $\chi^2$  (df) p: =147.9 (8) < 0.001; Time=0.923 (2) 0.630; Anosognosia groups=15.2 (2) 0.001; GDS=63.7 (2) < 0.001; GDS\*Anosognosia groups=13.1 (4) 0.011; Generalized linear model, Wald  $\chi^2$ , for GDS, anosognosia groups and interaction; Simple effects, Wald  $\chi^2$ , for differences between groups; Means, estimated marginal; SE, standard error; Significant with Bonferroni *post hoc* contrasts: <sup>a</sup>GDS 4–5, <sup>b</sup>GDS 4–6, <sup>c</sup>GDS 5–6; <sup>d</sup>1–2; <sup>e</sup>1–3; <sup>f</sup>2–3.

416 In most cost analyses, the severity of dementia  
 417 emerges as the main factor associated with increased  
 418 costs of informal care for people with AD [45]. As  
 419 expected, in our study, greater severity increased both  
 420 the number of hours of informal care required and  
 421 the use of health and social support services. How-  
 422 ever, the inclusion of the presence of anosognosia as  
 423 a variable in our analysis revealed important differ-  
 424 ences both in care hours and the use of resources. The  
 425 total cost of care increased in an almost linear manner

426 from mild cases of dementia without anosognosia, to  
 427 cases with incident or persistent anosognosia and at  
 428 GDS stage 6.

429 In cases without anosognosia and at GDS stage 4,  
 430 the monthly cost of care was over 830€, which is 1.29  
 431 times the minimum wage in Spain (648.60€/month)  
 432 [46]; it should be noted, however, that part of this  
 433 cost is borne by the government through dependency  
 434 allowances [47]: in the present study, this was the  
 435 case for 21.7% of patients with mild dementia and

84.8% of the most severe (GDS 6) cases. It should also be noted that while the figures obtained here are considerably high, the Catalan National Health System and Social Services subsidize part of the cost, which increases equitability. As for comparisons with previous research, the mean total cost of 1,787€/month is in line with the figures reported by other studies in Spain [40, 48], similar to the figures in Ireland [49], and slightly less than the cost documented in Germany, the UK, and France [50]. The cost of care increases with the severity of dementia, and most studies coincide in terms of the support services requested by caregivers and the factors that lead to greater care needs (functional disability and BPSD) [51]. The present study adds to this picture by showing that the presence of anosognosia is another factor that increases the cost of care over 300€/month on average.

Interestingly, we did not find an inverse relationship between the number of hours of informal care provided and the use of support services, which suggests that the availability of such services improves the quality of care provided, and the quality of life of patients and caregivers, rather than reducing the number of hours of informal care per se.

An increase in the amount of time spent by informal caregivers directly correlates with an increase in their perceived burden [52–54]. In a previous study we observed that the cost of informal care increased in line with the patient's physical disability and cognitive impairment, as well as if the relative was the sole caregiver, with the cost of informal care, explaining 6.7% of the total variance in the perceived burden of caregivers [40]. We also reported that the presence of anosognosia was a determining factor in terms of greater caregivers' perceived burden [20, 55]. The results of the present study highlight the need for more specific help to be offered to caregivers in relation to the impact that anosognosia in the patient can have, and the implications it has for home-based care [15, 53]. Future research may include a perceived economic burden measure, as well as some data regarding the "opportunity costs" related with a possible loss of opportunities due to the time spent as a caregiver. In the context of resource management, maintaining or improving the quality of life of patients and caregivers is one of the main ways in which the costs of health and social care can be reduced [56].

Previously, many studies examined the indirect cost based on caregivers' self-reported number of hours with no external validation. Also, our study

did not include the "opportunity costs" to caregivers and only included the "market price" for each hour reported. These limitations have influenced both the number of hours reported and the associated attributed cost. However, both figures are similar to those documented by other studies in Spain and internationally [24, 48–49]. Even though the resources and their access are not equal everywhere, we decided to describe their use in a specific work-class neighborhood of Barcelona where the possibilities and the accessibility were as similar as possible.

## CONCLUSIONS

Anosognosia is a frequent symptom in AD patients and it has a major impact to caregivers, increasing their time of care and the use of support services. The presence of anosognosia implies, therefore, an increase of informal costs.

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## SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: <http://dx.doi.org/10.3233/JAD-160419>.

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