



IX Congreso Nacional de
ALZHEIMER
10, 11, 12 y 13 de noviembre de 2021

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Impacto Económico de la enfermedad de Alzheimer: El papel de los costes sociales

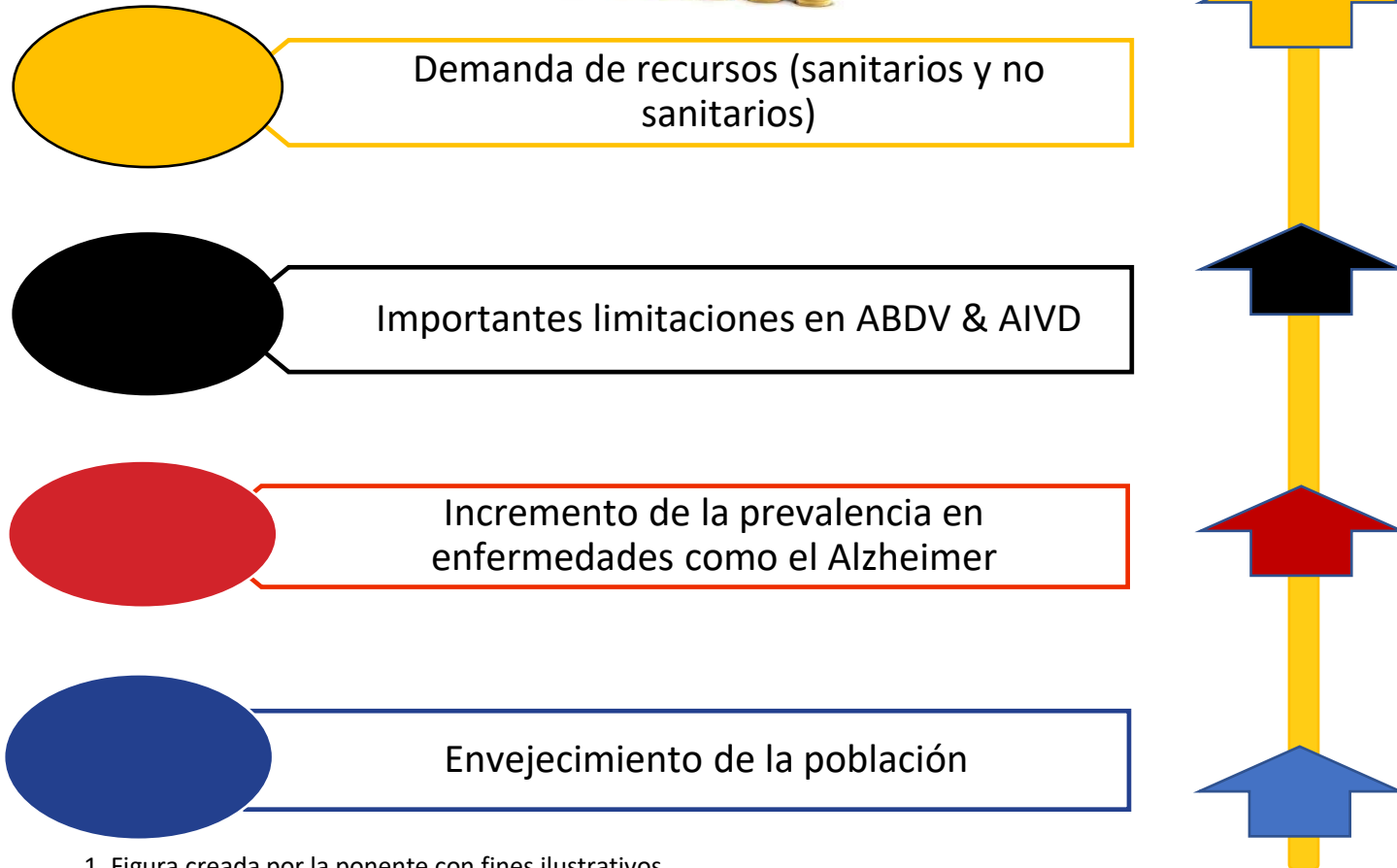
Luz María Peña Longobardo
Universidad de Castilla-La Mancha



GUIÓN

1. Contexto: La enfermedad de Alzheimer, el gran demandante de recursos
2. Impacto económico de la enfermedad de Alzheimer
3. El papel de los costes sociales en Alzheimer
4. Impacto no económico del Alzheimer
5. Reflexiones finales

1. Contexto: La enfermedad de Alzheimer, el gran demandante de recursos



1. Figura creada por la ponente con fines ilustrativos



Cuál es el impacto económico
de la enfermedad de Alzheimer



2. Impacto económico del Alzheimer



- ¿Qué utilidad tiene los estudios de coste de la enfermedad?



Aportan información sobre cuánto nos cuesta AD y/o cuánto nos podríamos ahorrar si prevenimos o reducimos el grado de severidad de la misma

- ¿Qué costes se tienen en cuenta?
- ¿Costes sanitarios (hospitalización, medicamentos, urgencias, etc...)?

2. Impacto económico del Alzheimer

ClinicoEconomics and Outcomes Research

Dovepress

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Open Access Full Text Article

ORIGINAL RESEARCH

Relationship between patient dependence and direct medical-, social-, indirect-, and informal-care costs in Spain

This article was published in the following Dove Press journal:
 ClinicoEconomics and Outcomes Research
 2 July 2015
[Number of times this article has been viewed](#)

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Objective: The objectives of this analysis were to examine how patients' dependence on others relates to costs of care and explore the incremental effects of patient dependence measured by the Dependence Scale on costs for patients with Alzheimer's disease (AD) in Spain.

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Table 4 Summary of costs over previous 6 months

Cost variables	Number of observations	Cost (€ 2013)	
		Mean (SD)	Median (IQR)
Direct medical care costs	343	1,028.12 (1,655.02)	530.80 (866.55)

Abbreviations: IQR, interquartile range; SD, standard deviation.

- Costes de hospitalización
- Costes de visitas a urgencias
- Costes de pruebas diagnósticas
- Coste de visitas AP& especialista
- Costes de material sanitario

2. Impacto económico del Alzheimer

Social-economic costs and quality of life of Alzheimer disease in the Canary Islands, Spain

Julio Lopez-Bastida, PhD; Pedro Serrano-Aguilar, PhD;
Lilisbeth Perestelo-Perez MPsych; and Juan Oliva-Moreno, PhD

Abstract—Objectives: To examine the economic burden (direct and indirect costs) of Alzheimer disease (AD) and analyze the impact on health-related quality of life (HRQOL) for patients with AD and caregivers in 2001 in the Canary Islands, Spain. **Methods:** Two hundred thirty-seven patients (61% of those contacted) were recruited from the Alzheimer Disease Association in the Canary Islands. Demographic, health resources utilization, informal care, indirect costs, and quality of life data were collected from primary caregivers of patients as proxy respondents. HRQOL was measured for patients and caregivers with the generic questionnaire EQ-5D. **Results:** The average annual cost per patient with AD was €28,198 (US \$36,144). The most important categories of costs were for informal care and drugs. Costs increased with cognitive impairment with an average annual cost of €14,956 (US \$19,171) for mild, €25,562 (US \$32,765) for moderate and €41,669 (US \$53,411) for severe patients. The total cost of patients with AD in Canary Islands was €259 (US \$33 million). The HRQOL with the EQ-5D social tariff was 0.29 for patients and 0.67 for caregivers. The EQ-5D VAS (thermometer) score was 42 for patients and 62 for caregivers. **Conclusions:** Direct health care costs of AD represent 2.4% of the total public health care expenditure in the Canary Islands. Across all severity levels, we estimated a total annual cost of €10 (US \$13) billion for AD patients older than 65 years in Spain. The degree of severity of the patients with AD substantially influenced the quality of life of the patients but not that of the caregivers.

NEUROLOGY 2006;67:2186-2191

Neurology. 2006 Dec 26;67 (12):2186-9

Table 2 Mean annual cost per patient with AD (mild, moderate, and severe)

	Mild (n = 47)	Moderate (n = 95)	Severe (n = 95)	Total (n = 237)
Direct health care costs, € (\$)				
Hospital care	€40 (US \$51)	€368 (US \$472)	€1,146 (US \$1,469)	€619 (US \$793)
Medical visits (public)	€188 (US \$241)	€189 (US \$242)	€158 (US \$203)	€176 (US \$226)
Medical visits (private)	€64 (US \$82)	€68 (US \$87)	€77 (US \$99)	€71 (US \$91)
Drugs	€1,988 (US \$2,548)	€2,046 (US \$2,623)	€1,561 (US \$2,001)	€1,836 (US \$2,353)
Medical tests and examinations	€121 (US \$155)	€141 (US \$181)	€127 (US \$163)	€131 (US \$168)
Emergencies	€35 (US \$45)	€60 (US \$77)	€94 (US \$120)	€68 (US \$87)
Medical home care	€20 (US \$26)	€52 (US \$67)	€324 (US \$415)	€157 (US \$201)
Orthopedic devices	€46 (US \$59)	€162 (US \$208)	€389 (US \$499)	€231 (US \$296)
Health care transport	€45 (US \$58)	€72 (US \$92)	€61 (US \$78)	€62 (US \$79)
Day centers	€274 (US \$351)	€352 (US \$451)	€143 (US \$183)	€250 (US \$320)
Geriatric residences	€0 (US \$0)	€87 (US \$112)	€81 (US \$104)	€67 (US \$86)
Subtotal	€2,821 (US \$3,616)	€3,597 (US \$4,611)	€4,161 (US \$5,334)	€3,668 (US \$4,702)



2. Impacto económico del Alzheimer

En Europa...

Journal of Alzheimer's Disease 27 (2011) 187–196
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187

Cost of Dementia in the Pre-Enlargement Countries of the European Union

Ramon Luengo-Fernandez*, Jose Leal and Alastair M. Gray
Health Economics Research Centre, Department of Public Health, Old Road Campus, University of Oxford, Oxford, UK

2. Impacto económico del Alzheimer

Costs of dementia (€ millions) in the EU-15, by country, 2007

Country	Health and social care costs						Productivity losses		Informal care costs (€)	TOTAL COSTS (€)	
	Primary care (€)	Outpatient care (€)	A&E (€)	Inpatient care (€)	Medications (€)	Long-term institutional care (€)	Total (€)	Mortality (€)			Morbidity (€)
Austria	114	58	15	138	55	925	1,305	1	0.04	2,360	3,706
Belgium	51	6	9	80	46	1,121	1,313	7	0.05	2,870	4,237
Denmark	12	12	7	16	20	1,177	1,244	8	0.05	3,826	5,124
Finland	16	17	3	889	46	288	1,259	10	0.03	3,006	4,301
France	280	86	54	278	348	9,137	10,183	27	0.23	13,536	23,980
Germany	1,569	444	75	310	390	12,606	15,394	30	0.43	23,311	39,165
Greece	17	55	6	30	81	204	393	6	0.04	3,160	3,595
Ireland	29	19	12	16	12	229	317	3	0.02	1,868	2,210
Italy	244	282	25	120	95	3,581	4,348	19	0.21	28,659	33,236
Luxembourg	2	1	<1	4	2	108	117	1	<0.01	109	230
Netherlands	71	15	6	66	12	1,368	1,539	12	0.09	3,683	5,323
Portugal	48	38	10	5	32	382	514	6	0.02	2,116	2,655
Spain	183	195	43	149	283	2,242	3,094	18	0.12	11,321	14,557
Sweden	115	43	6	39	37	2,751	2,990	11	0.05	4,857	7,910
UK	380	97	45	1,427	135	12,435	14,519	58	0.37	24,104	39,050
Total EU-15	3,132	1,369	315	3,567	1,593	48,555	58,530	218	2	128,787	189,280



Cuál es el papel de los costes sociales en AD



**Son importantes los cuidados no profesionales
(informales) en AD**



Por qué



3. El papel de los costes sociales en Alzheimer

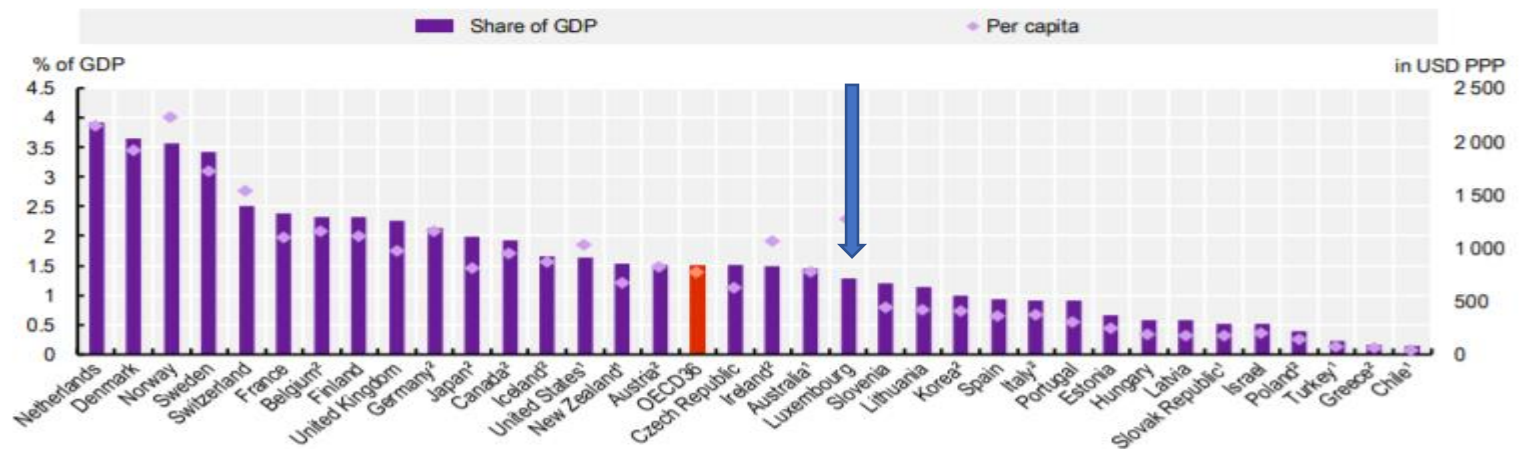
- Durante la última década, los cuidados informales han sido un recurso prácticamente invisible para los responsables políticos
- Sin embargo, los cambios demográficos y sociales acaecidos están modificando la percepción social de ello
- Los sistemas de atención a la dependencia en Europa están formados por modelos mixtos donde el papel del Estado y las familias comparte la responsabilidad del cuidado personal

3. El papel de los costes sociales en Alzheimer

¿Qué esfuerzo (en términos económicos) se hace a la atención a la dependencia?

- España es uno de los países con un esfuerzo en gasto de atención al dependiente más bajo (0,8% vs 1,7%)

Figure 1. Total LTC expenditure as share of GDP and per capita, 2018 (or nearest year)



1. Estimated by the OECD Secretariat. 2. Countries not reporting spending for LTC (social). In many countries this component is therefore missing from total LTC but in some countries it is partly included under LTC (health). Colombia became an OECD member after the 2020 data collection and is missing from the chart.

Source: OECD Health Statistics 2020, <https://doi.org/10.1787/health-data-en>; Mueller, Bourke and Morgan. (2020^[1]) "Assessing the comparability of Long-Term Care spending estimates under the Joint Health Accounts Questionnaire", <https://www.oecd.org/health/health-systems/LTC-Spending-Estimates-under-the-Joint-Health-Accounts-Questionnaire.pdf>.

3. El papel de los costes sociales en Alzheimer

Tabla. Modelos de cuidados de larga duración en Europa

	Modelo escandinavo	Modelo continental	Modelo liberal	Modelo mediterráneo
Países	Suecia, Noruega, Finlandia	Alemania, Francia, Austria	Reino Unido, EEUU	Italia, España
Tipo de cobertura	Universal	Universal	Asistencial	Asistencial
Financiación	Impuestos	Cotizaciones sociales	Impuestos	Impuestos
Nivel de copago del usuario	Bajo (según renta y tipo de servicio)	Medio (sobre costes)	Alto (según renta+patrimonio y coste)	Alto
Peso del cuidado informal sobre el total	Bajo	Medio	Medio	Alto
Remuneración del cuidador informal	Relativamente elevada	Variable entre países	Reducida	Reducida o nula
Protección social del cuidador informal	Alta (formación, apoyo, empleo, servicios de respiro)	Alta (excedencia laboral, servicios de respiro, vacaciones, formación)	Media (asesoramiento, formación, exenciones fiscales)	Reducida
Apoyo social a domicilio	Alto	Medio	Medio	Bajo
Peso de la provisión privada sobre el total	Bajo	Medio	Alto	Alto
Tipo de prestación mayoritaria	En especie	En especie-monetaria	En especie-monetaria	Monetaria
Ámbito competencial de las ayudas	Estatual-municipal	Estatual-regional	Estatual-local	Regional
Gasto en CLD sobre PIB	>2%	1-1,5%	≈1%	<1%
Porcentaje del gasto público sobre gasto en CLD	>80%	30-80%	60-70%	<30%
Otras características	Elevado desarrollo de los servicios comunitarios	Seguro privado obligatorio en Alemania	Elevado peso de la prestación privada	Desigualdades territoriales notables

3. El papel de los costes sociales en Alzheimer

- La Ley de promoción de la autonomía personal y el cuidado de las personas dependientes, aprobada en diciembre de 2006, tenía por objeto cambiar el modelo de atención de las personas dependientes.
- El objetivo inicialmente propuesto era brindar atención profesional en el hogar, excepto en los casos de alto grado de dependencia y falta de apoyo familiar.
- Sin embargo, contrariamente a este espíritu, los beneficios monetarios se han convertido en una práctica habitual, especialmente los beneficios monetarios para los cuidadores.

¿Por qué?

3. El papel de los costes sociales en Alzheimer

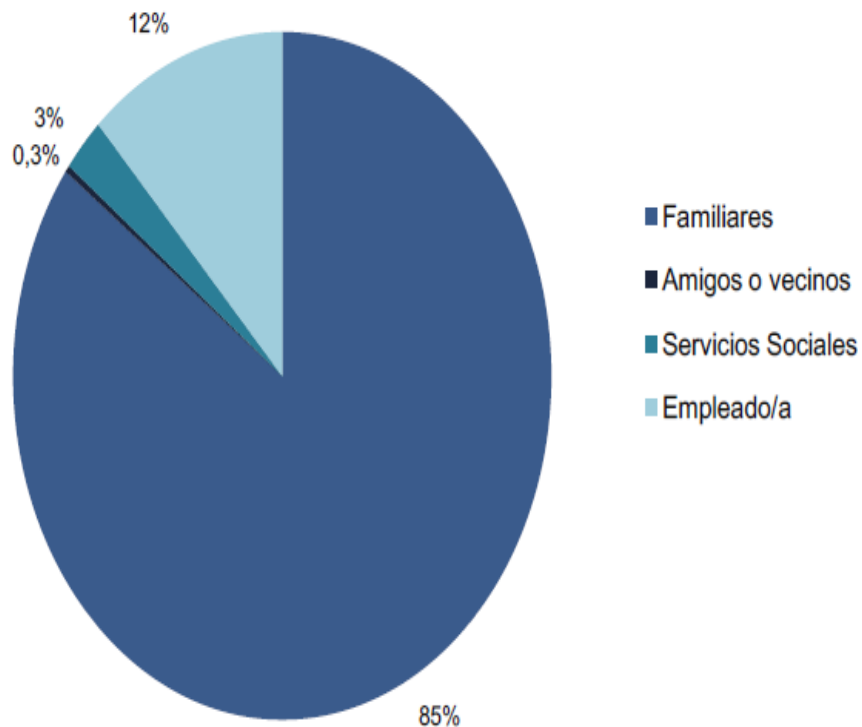
- Una mayor preferencia de las personas dependientes de ser cuidados por familiares y amigos en el hogar por razones culturales, pero también económicas, especialmente debido a los efectos de la pasada crisis económica cuando en España había un número creciente de personas en riesgo de pobreza o exclusión social ¹
- Los beneficios económicos para las familias que cuidan son más baratos que los beneficios en especie (crisis: recortes muy altos en los presupuestos del sistema de atención) ²

Observatorio Europeo de Sistemas y Políticas de Salud

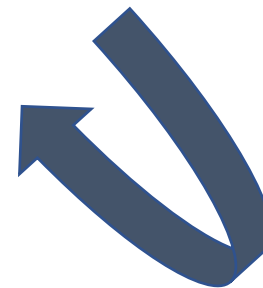
3. El papel de los costes sociales en Alzheimer

GRÁFICO 7.9

CUIDADOR PRINCIPAL DE LA POBLACIÓN DE 65 Y MÁS AÑOS CON DISCAPACIDAD, ESPAÑA 2008 (%)



El peso de los cuidados informales (familiares) es muy relevantes dentro del SAAD



¿

Los cuidados informales son
gratis ?



NO..... (nada es gratis)

3. El papel de los costes sociales en Alzheimer

ClinicoEconomics and Outcomes Research

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ORIGINAL RESEARCH

Relationship between patient dependence and direct medical-, social-, indirect-, and informal-care costs in Spain

Darba J, et la. Clinicoecon Outcomes Res. 2015; 7: 387-395

This article was published in the following Dove Press journal: ClinicoEconomics and Outcomes Research
2 July 2015
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¹Department of Economics, University of Barcelona, ²BCN Health Economics and Outcomes Research SL, Barcelona, Spain

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Social care costs	343	843.85 (2,684.83)	0.02 (62.81)
Indirect care costs	343	464.21 (1,639.01)	0.01 (0.02)
Informal care costs	308	33,232.20 (30,898.92)	24,272.02 (42,134.24)
Total care costs	343	32,177.34 (31,836.95)	21,093.34 (43,201.84)

Abbreviations: IQR, interquartile range; SD, standard deviation.

Cada aumento adicional de un punto en la puntuación de DS, se asoció con:

- Un aumento del 13,5% en los costes de atención médica,
- Un aumento del 25,3% en los costes de atención social
- Un aumento del 214,7% en los costes de atención informal

3. El papel de los costes sociales en Alzheimer

Journal of Alzheimer's Disease 27 (2011) 187–196
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Total EU-15	3,132	1,369	315	3,567	1,593	48,555	58,530	218	2	128,787	189,280
						5,27%	25,65%		0,12%	68,04%	
						5,88%	15,40%		0,12%	77,77%	

Social-economic costs and quality of life of Alzheimer disease in the Canary Islands, Spain

Julio Lopez-Bastida, PhD; Pedro Serrano-Aguilar, PhD;
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Lopez-Bastida J, et la. *Neurology*. 2006 Dec 26;67(12):2186-91.

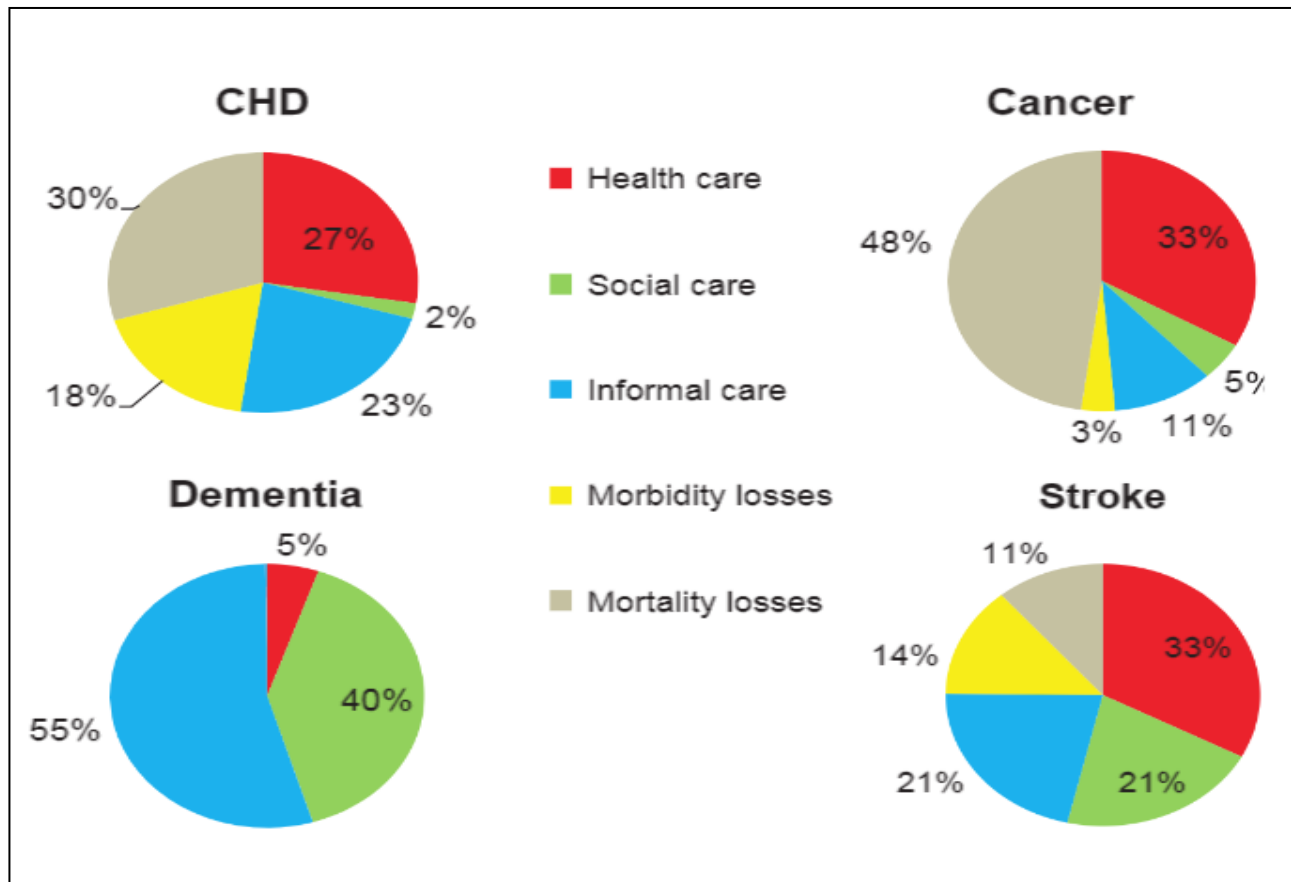
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Health care transport	€45 (US \$58)	€72 (US \$92)	€61 (US \$78)	€62 (US \$79)
Day centers	€274 (US \$351)	€352 (US \$451)	€143 (US \$183)	€250 (US \$320)
Geriatric residences	€0 (US \$0)	€87 (US \$112)	€81 (US \$104)	€67 (US \$86)
Subtotal	€2,821 (US \$3,616)	€3,597 (US \$4,611)	€4,161 (US \$5,334)	€3,668 (US \$4,702)
Direct non-health care costs, € (\$)				
Principal caregiver	€7,642 (US \$9,796)	€14,887 (US \$19,082)	€26,609 (US \$34,107)	€16,723 (US \$21,436)
Secondary caregiver	€3,206 (US \$4,109)	€4,922 (US \$6,309)	€7,354 (US \$9,426)	€5,290 (US \$6,781)
Voluntary service	€56 (US \$72)	€280 (US \$359)	€282 (US \$361)	€234 (US \$300)
Domestic cleaner (private)	€668 (US \$856)	€1,045 (US \$1,339)	€1,515 (US \$1,942)	€1,159 (US \$1,486)
Home support (social services)	€24 (US \$31)	€220 (US \$282)	€993 (US \$1,273)	€496 (US \$636)
Subtotal	€11,596 (US \$14,864)	€21,354 (US \$27,372)	€36,753 (US \$47,110)	€23,902 (US \$30,638)
Total, direct costs	€14,417 (US \$18,480)	€24,951 (US \$31,982)	€40,914 (US \$52,444)	€27,570 (US \$35,339)
Indirect costs, € (\$)				
Early retirement (patient)	€539 (US \$691)	€611 (US \$783)	€755 (US \$968)	€628 (US \$805)
Subtotal	€539 (US \$691)	€611 (US \$783)	€755 (US \$968)	€628 (US \$805)
Total costs	€14,956 (US \$19,171)	€25,562 (US \$32,765)	€41,669 (US \$53,411)	€28,198 (US \$36,144)

AD = Alzheimer disease.

3. El papel de los costes sociales en Alzheimer

¿La magnitud de los cuidados es similar en todas las enfermedades?



Fuente: Luengo-Fernandez, R, et al. J Alzheimer Dis. 2011;27(1): 187-96

Gráficos desarrollados por ponente

3. El papel de los costes sociales en Alzheimer

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DOI 10.1007/s10198-014-0604-6



ORIGINAL PAPER

Economic valuation and determinants of informal care to people with Alzheimer's disease

Luz María Peña-Longobardo · Juan Oliva-Moreno

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Abstract

Objective To estimate the monetary value of informal care to people with Alzheimer's disease (AD) in Spain and to identify the main determinants of the time of informal care.

Data and methods We used the Survey on Disabilities, Autonomy and Dependency carried out in Spain in 2008 to obtain information on disabled individuals with Alzheimer and their informal caregivers. Assessment of informal care time was performed using three different approaches: the proxy good method, the opportunity cost method and the contingent valuation method. A statistical multivariate analysis—an ordered probit model—was performed to study the determinants of informal care provided.

Conclusions Informal care represents a high social cost in people with AD, regardless of the estimation method considered. A higher level of dependence is associated with more hours of informal care provided.

Keywords Economic value · Social costs · Informal care · Revealed preference methods · Contingent valuation · Alzheimer's disease

JEL Classification I1 · I3 · D1 · D6 · J14

Introduction

- ¿Y si los cuidadores informales de las personas con AD desaparecieran
- ¿Cuál sería el volumen de servicios sociales formales necesario para cubrir dicha ausencia?
- ¿Cuál es el coste de oportunidad de los cuidadores informales?
- ¿Cómo valoran (económicamente) los cuidadores informales el cuidado prestado?

3. El papel de los costes sociales en Alzheimer

Table 2 Value of informal care (main caregivers) using three alternatives methods

	Value of informal care ^a (SD)	
	With restriction	Without restriction
Proxy good method; Scenario 1	52,760.64 (20,761)	69,240.14 (34,947)
Proxy good method; Scenario 2	31,839.04 (12,529)	41,783.78 (21,089)
Opportunity cost method	20,053.21 (7,700)	25,574.30 (12,502)
Contingent valuation method; Scenario 1	18,680.01 (7,350)	24,515.38 (12,373)
Contingent valuation method; Scenario 2	22,831.12 (8,984)	29,963.25 (15,122)
Contingent valuation method; Scenario 3	29,057.79 (11,434)	38,135.04 (19,247)

Source Authors of this paper using data from EDAD-08

^a Average cost per year

Fuente: Peña-Longobardo L M, et al. Eur J Health Econ. 2015 Jun;16(5):507-15

Asociación positiva entre el grado de dependencia y el número de horas de atención no profesional (coste informal)



Table 3 Determinants of informal caregiving hours provided

	High caregiving hours		Medium caregiving hours		Low caregiving hours	
	dy/dx (SD)	p	dy/dx (SD)	p	dy/dx (SD)	p
Moderate dependence	0.076 (0.053)	0.141	-0.033 (0.025)	0.183	-0.043 (0.028)	0.126
Severe dependence	0.198 (0.045)	0.000***	-0.094 (0.025)	0.000***	-0.106 (0.022)	0.000***
Heavy dependence	0.258 (0.042)	0.000***	-0.105 (0.019)	0.000***	-0.155 (0.026)	0.000***
Formal care in-home	0.084 (0.048)	0.059*	-0.037 (0.022)	0.087*	-0.047 (0.023)	0.044**
Formal care out-of-home	-0.197 (0.041)	0.000***	0.059 (0.010)	0.000***	0.139 (0.033)	0.000***
N	903					
LR χ^2	190.80					
Prob > χ^2	0.000					
Pseudo R ²	0.103					

Fuente: Peña-Longobardo L M, et al. Eur J Health Econ. 2015 Jun;16(5):507-15

Results of the ordered probit model

Significance level at 99 % (***), at 95 % (**) and at 90 % (*). Dependent variable: Weekly caregiving hours. Control variables: age, gender, educational level, marital status and economic activity of the caregiver, level of income, degree of dependency, size of the municipality where the patient resides, Autonomous Community, formal in-home care received and formal out-of-home care received. Source: Authors of this paper using data from EDAD-08

3. El papel de los costes sociales en Alzheimer

¿Y las evaluaciones económicas en AD?



- Añadir a las condiciones de eficacia, seguridad y calidad (básicas para la aprobación de una tecnología sanitaria)...
- ...un cuarto elemento: **eficiencia** (balance entre el coste y el valor terapéutico o social en términos relativos)
- Ligar este elemento al precio de la tecnología, a su financiación pública y al uso de la misma en la práctica habitual.
 - **¿Qué efecto podrían tener los costes no sanitarios en los Resultados/conclusiones de las EE en AD?**
 - **¿Cambiarían las recomendaciones de las EE en las intervenciones en AD?**

3. El papel de los costes sociales en Alzheimer

The European Journal of Health Economics
<https://doi.org/10.1007/s10198-019-01087-6>

ORIGINAL PAPER



How relevant are social costs in economic evaluations? The case of Alzheimer's disease

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Abstract

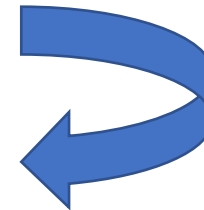
Background The main objective of this study was to analyse how the inclusion (exclusion) of social costs can alter the results and conclusions of economic evaluations in the field of Alzheimer's disease interventions.

Methods We designed a systematic review that included economic evaluations in Alzheimer's disease. The search strategy was launched in 2000 and ran until November 2018. The inclusion criteria were: being an original study published in a scientific journal, being an economic evaluation of any intervention related to Alzheimer's disease, including social costs (informal care costs and/or productivity losses), being written in English, using QALYs as an outcome for the incremental cost–utility analysis, and separating the results according to the perspective applied.

Results It was finally included 27 studies and 55 economic evaluations. Around 11% of economic evaluations changed their main conclusions. More precisely, three of them concluded that the new intervention became cost-effective when the societal perspective was considered, whereas when using just the health care payer perspective, the new intervention did not result in a cost–utility ratio below the threshold considered. Nevertheless, the inclusion of social cost can also influence the results, as 37% of the economic evaluations included became the dominant strategy after including social costs when they were already cost-effective in the health care perspective.

Conclusions Social costs can substantially modify the results of the economic evaluations. Therefore, taking into account social costs in diseases such as Alzheimer's can be a key element in making decisions about public financing and pricing of health interventions.

Objetivo



Analizar si las evaluaciones económicas en el ámbito de la enfermedad de Alzheimer cambian sus conclusiones y recomendaciones sobre financiación y aceptación de nuevas tecnologías sanitarias en AD cuando se tienen en cuenta los costes sociales de la enfermedad

3. El papel de los costes sociales en Alzheimer

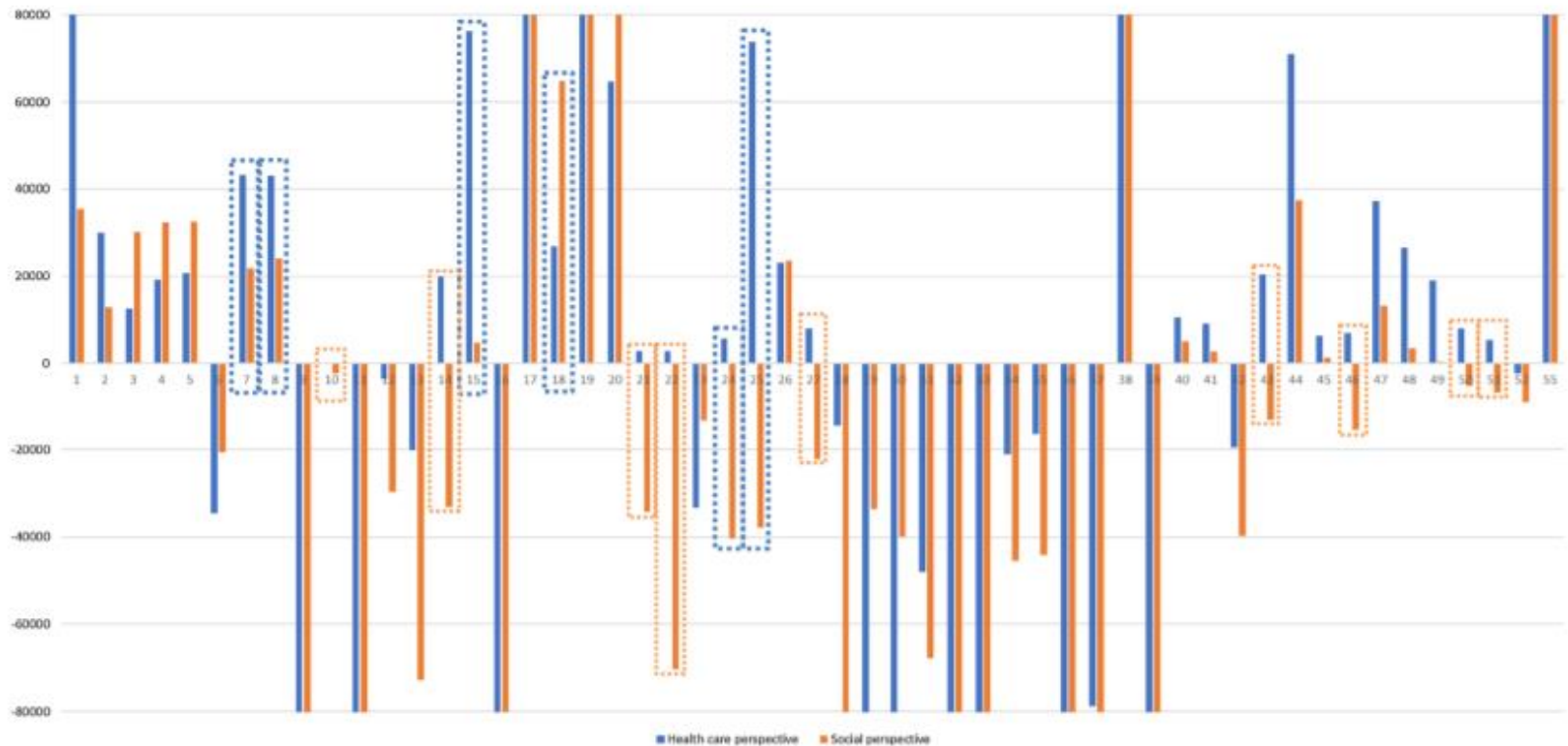
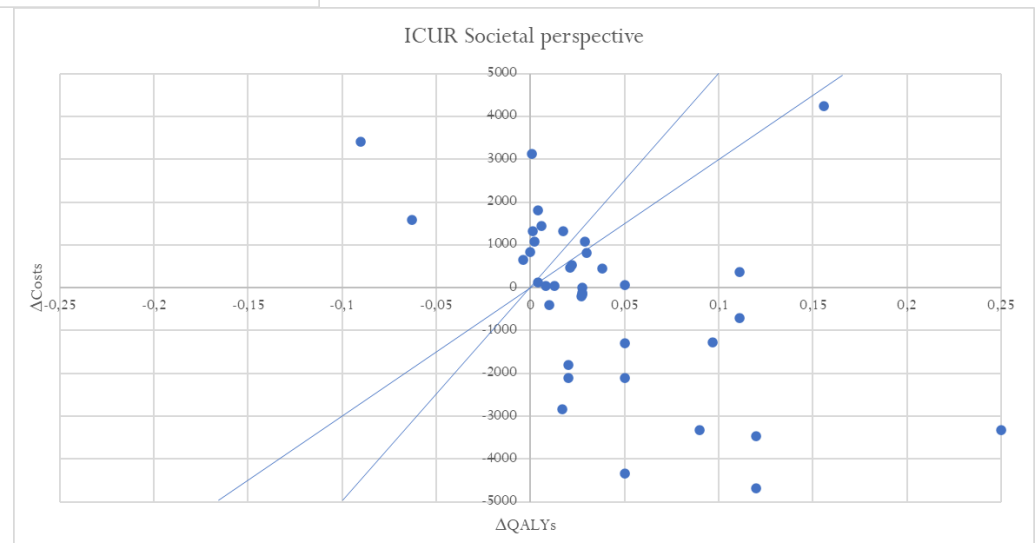
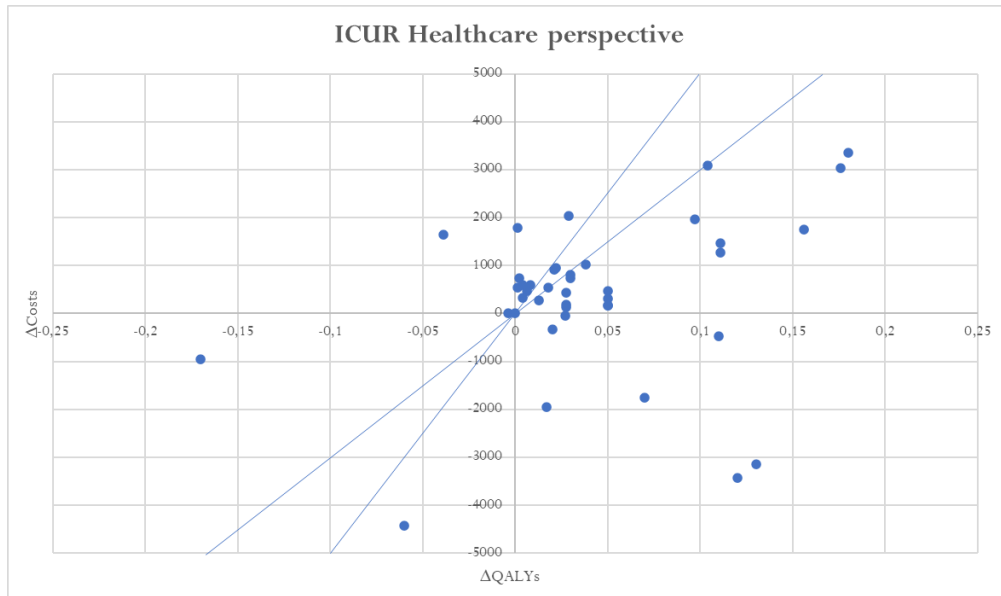


Fig. 2 Incremental Cost–Utility Ratios (ICUR) in Alzheimer’s disease interventions: Healthcare and Societal perspectives. *Note:* estimations within a blue square denote that when social costs are included, the conclusions about the cost–effectiveness of the intervention change. Estimations within an orange square mean that if social

costs are considered, incremental costs switch from positive incremental costs to negative incremental costs. Estimations number 53 and 54 are not included in this figure, because it was not possible to obtain the ICUR value

3. El papel de los costes sociales en Alzheimer



Figuras realizadas por ponente, teniendo en cuenta datos obtenidos en artículo:Peña-Longobardo L M, et al. Eur J Health Econ. 2019 Nov;20(8): 1207-1236

3. El papel de los costes sociales en Alzheimer

- Los resultados mostraron que en el 11% de las EE cambiaron sus principales conclusiones cuando se incluyeron los costes sociales.
- Más precisamente, en la mitad de ellas, la nueva intervención se volvió coste-efectiva cuando se consideró la perspectiva social, al contrario de lo que ocurrió cuando se utilizó solo la perspectiva del pagador de la atención médica.
- El factor que explicó principalmente este cambio fue que los costes del cuidado informal fueron muy diferentes en la nueva intervención vs. su comparador.
- Sin embargo, en las evaluaciones económicas restantes mostraron el patrón opuesto, lo que condujo a ahorros de costes desde la perspectiva del pagador de atención médica, pero con costes crecientes desde la perspectiva social.



Cuál es el impacto NO económico de la enfermedad de Alzheimer



Problemas sobre la salud

Problemas en la vida profesional

Problemas en la vida social

4. Impacto NO económico de Alzheimer

Journal of Alzheimer's Disease 40 (2014) 1–10
DOI 10.3233/JAD-141374
IOS Press

Caregiver Burden in Alzheimer's Disease Patients in Spain

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Accepted 23 July 2014

Abstract.

Background: Alzheimer's disease constitutes one of the leading causes of burden of disease, and it is the third leading disease in terms of economic and social costs.

Objective: To analyze the burden and problems borne by informal caregivers of patients who suffer from Alzheimer's disease in Spain.

Data and Methods: We used the Survey on Disabilities, Autonomy and Dependency to obtain information on the characteristics of disabled people with Alzheimer's disease and the individuals who provide them with personal care. Additionally, statistical multivariate analyses using probit models were performed to analyze the burden placed on caregivers in terms of health, professional, and leisure/social aspects.

Results: 46% of informal caregivers suffered from health-related problems as a result of providing care, 90% had leisure-related problems, and 75% of caregivers under 65 years old admitted to suffering from problems related to their professional lives. The probability of a problem arising for an informal caregiver was positively associated with the degree of dependency of the person cared for. In the case of caring for a greatly dependent person, the probability of suffering from health-related problems was 22% higher, the probability of professional problems was 18% higher, and there was a 10% greater probability of suffering from leisure-related problems compared to non-dependents.

Conclusions: The results show a part of the large hidden cost for society in terms of problems related to the burden lessened by the caregivers. This information should be a useful tool for designing policies focused toward supporting caregivers and improving their welfare.

Keywords: Alzheimer's disease, burden, caregivers, informal care, social costs

1

Table 2

Percentage of informal caregivers who suffer from health, professional, and leisure-related problems

	Greatly Dependent	Severely Dependent	Moderately Dependent	Non-Dependent	Total*
<i>Health-Related Problems (n = 904)</i>					
Global	58.8	40.5	26.9	35.8	46.1
Treatment	29.5	15.0	0.2	19.9	21.6
Feel Tired	75.7	63.5	42.5	54.0	64.3
Feel Depressed	46.9	36.4	28.3	38.5	40.3
Other health-related problems	11.9	13.8	7.8	12.1	11.7
<i>Leisure-Related Problems (n = 904)</i>					
Global	95.8	91.6	81.4	81.2	90.4
Decreased Leisure Time	82.8	74.2	56.6	66.0	74.2
Decreased Holiday Time	73.3	55.1	41.5	53.5	61.3
Conflict with partner	11.5	7.6	2.6	8.0	8.7
Time with Friends	66.2	57.6	35.4	38.3	55.2
Family Time	3.5	2.5	2.6	0.8	2.7
Self-care Time	62.7	47.4	36.2	43.7	52.2
<i>Professional-Related Problems** (n = 645)</i>					
Global	81.1	72.3	68.7	64.7	75.1
Give up job	22.3	18.1	10.9	17.0	19.1
Cannot work out of the home	40.7	39.0	21.8	36.7	37.2
Decreased Working Time	14.1	10.4	18.7	8.8	13.1
Deterioration of Working life	15.4	7.6	14.0	19.1	14.0
Can't stick to schedule	14.5	12.3	9.3	14.7	13.4
Economic Problems	24.0	19.0	10.9	23.5	21.0

*Above total informal caregivers. **Only informal caregivers under 65 years old. Source: Authors of this paper using data from EDAD-08.

4. Impacto NO económico de Alzheimer

¿Cuántas horas/semana en media de atención dedican las personas cuidadoras no profesionales a enfermos con Alzheimer en España?

Hours of caregiving provided per week

Not dependent	64.41* (81.4)**
Moderately dependent	72.90* (92.7)**
Severely dependent	84.9* (110.7)**
Greatly dependent	85.2 (114.2)*

4. Impacto NO económico de Alzheimer

- El grado de severidad está asociado a la carga soportada por los cuidados no profesionales
- Solo se encontraron diferencias estadísticamente significativa en personas grandes dependientes

Impacto sobre la salud

Table 3
Caregivers' burden: Health problems. Probit Model Results

	Health-Global		Treatment		Feel Tired		Feel Depressed		Other health problems	
	dy/dx (S.D)	p	dy/dx (S.D)	p	dy/dx (S.D)	p	dy/dx (S.D)	p	dy/dx (S.D)	p
Moderately dependent	-0.122 (0.062)	0.057	-0.107 (0.036)	0.017*	-0.134 (0.061)	0.023*	-0.117 (0.056)	0.049	-0.042 (0.030)	0.216
Severely dependent	0.020 (0.059)	0.732	-0.033 (0.041)	0.441	0.067 (0.050)	0.193	-0.037 (0.055)	0.504	0.024 (0.036)	0.477
Greatly dependent	0.221 (0.505)	0.000**	0.079 (0.038)	0.037*	0.208 (0.045)	0.000**	0.078 (0.048)	0.107	-0.000 (0.029)	0.973
N		904		904		904		904		904
Prob>chi2		0.0000		0.0000		0.0000		0.0000		0.5610
Pseudo R2		0.1421		0.1188		0.1260		0.0854		0.0521

Significance level at 99% (**) and at 95% (*). Control variables: age, gender, educational level, marital status and economic activity of the caregiver, level of income, degree of dependency, size of the municipality where the patient resides, Autonomous Community, formal in-home care received and formal out-of-home care received. Interested readers may refer to the complete tables of results.

4. Impacto NO económico de Alzheimer Impacto sobre la vida profesional

Table 4
Caregivers' burden: Work-related problems. Probit Model Results

	Work Global		Give up work		Decreased time at work		Deterioration of working life		Cannot meet schedule		Economic Problems	
	dy/dx (S.D)	p	dy/dx (S.D)	p	dy/dx (S.D)	p	dy/dx (S.D)	p	dy/dx (S.D)	p	dy/dx (S.D)	p
Moderately dependent	0.061 (0.062)	0.701	-0.031 (0.069)	0.667	0.111 (0.083)	0.118	-0.021 (0.042)	0.632	-0.029 (3.720)	0.417	-0.090 (0.057)	(0.057)
Severely dependent	0.105 (0.053)	0.014*	0.024 (0.067)	0.712	0.043 (0.065)	0.479	-0.071 (0.032)	0.063	-0.001 (0.129)	0.977	-0.039 (0.058)	(0.058)
Greatly dependent	0.186 (0.057)	0.000**	0.072 (0.056)	0.196	0.080 (0.050)	0.113	-0.010 (0.038)	0.795	0.000 (0.108)	0.978	0.026 (0.055)	(0.055)
N		470		450		454		438		435		460
Prob>chi2		0.0027		0.3069		0.4221		0.0000		0.0004		0.0146
Pseudo R2		0.1140		0.0765		0.0881		0.2078		0.1749		0.1083

Significance level at 99% (**) and at 95% (*). Control variables: age, gender, educational level, marital status and economic activity of the caregiver, level of income, degree of dependency, size of the municipality where the patient resides, Autonomous Community, formal in-home care received and formal out-of-home care received. Interested readers may refer to the complete tables of results.

Impacto sobre la vida social

Table 5
Caregivers' burden: Social problems. Probit Model Results

	Social Global		Reduction of leisure time		Cannot go on holidays		Conflict with partner		No time for friends		Cannot have family		No time for self-care	
	dy/dx (S.D)	p	dy/dx (S.D)	p	dy/dx (S.D)	p	dy/dx (S.D)	p	dy/dx (S.D)	p	dy/dx (S.D)	p	dy/dx (S.D)	p
Moderately Dependent	0.009 (0.023)	0.701	-0.086 (0.061)	0.138	-0.119 (0.069)	0.080	-0.048 (0.017)	0.066	-0.012 (0.071)	0.864	0.034 (0.043)	0.124	-0.056 (0.072)	0.431
Severely Dependent	0.052 (0.017)	0.014*	0.065 (0.047)	0.190	0.009 (0.061)	0.876	0.009 (0.028)	0.726	0.214 (0.057)	0.001**	0.017 (0.025)	0.258	0.034 (0.065)	0.597
Greatly Dependent	0.107 (0.024)	0.000**	0.150 (0.0450)	0.001**	0.196 (0.052)	0.000**	0.026 (0.023)	0.254	0.293 (0.053)	0.000**	0.010 (0.012)	0.246	0.189 (0.056)	0.001**
N		719		719		719		684		719		433		719
Prob>chi2		0.0004		0.0000		0.0000		0.0001		0.0000		0.0001		0.0000
Pseudo R2		0.1563		0.1431		0.1064		0.1750		0.1067		0.4032		0.1113

Significance level at 99% (**) and at 95% (*). Control variables: age, gender, educational level, marital status and economic activity of the caregiver, level of income, degree of dependency, size of the municipality where the patient resides, Autonomous Community, formal in-home care received and formal out-of-home care received. Source: Authors of this paper using data from EDAD-08. Interested readers may refer to the complete tables of results.



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¿

EN SUMA...

?

5. Reflexiones final

- El coste que suponen los costes de atención no profesional superan los costes sanitarios
- Los costes sociales pueden tener un efecto importante en la toma de decisiones en la financiación y en el uso de tecnologías sanitarias en AD
- El abordaje integral de los cuidados de las personas dependientes, exige incluir el papel y la atención al cuidador principal de dichas personas y un reconocimiento social de primer orden sobre el papel cumplido por los cuidadores.
- La sobrecarga que soportan los cuidadores generan una serie de problemas en su salud, en su vida profesional y en su tiempo de ocio y de vida familiar no debe considerarse en ningún caso un problema menor.
- El desarrollo de estrategias de apoyo a las personas cuidadoras presentan un elevado potencial de mejoras del bienestar, tanto de los cuidadores como probablemente de las personas cuidadas.

5. Reflexiones final

“No hay que olvidar que es fundamental cuidar al que cuida, es más, esta es una de las labores principales del médico tratante: no centrarse sólo en el paciente, sino también en quienes están apoyándolo”.



“Si no cuidamos de los cuidadores, no tendremos un enfermo, sino dos.”

-Pedro Simón

5. Reflexiones final

“When we dine where the menu has no prices, we should not be surprised by the size of the bill.”

Alan M. Garber (*Ann Intern Med.* 2008)



IX Congreso Nacional de
ALZHEIMER
10, 11, 12 y 13 de noviembre de 2021

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¡Muchas gracias por su atención!

Luz María Peña Longobardo

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