Assessing the experiences of informal caregivers of patients with mild cognitive impairment using self-reported measures

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What does this mean for the AD community?
- By understanding caregiver's stress and burden we may help them to provide better assistance to people with MCI.

Conclusions
- Informal caregivers of people with MCI in Spain experience significant stress. The identification of factors contributing to their stress can assist healthcare professionals in implementing specific early interventions to address these challenges.

Background

- Alzheimer's disease (AD) is a progressive, neurodegenerative disease considered the most common form of dementia, accounting for 60-80% of cases worldwide, with a significant prevalence in Spain (approximately 800,000 people affected)[1].
- Early symptoms of AD, including memory loss and mood changes, progress to a loss of daily living activities in advanced stages, necessitating external care[2,3].
- In 85% of cases, the caregiver is a close relative, often a woman, highlighting the socio-sanitary impact of AD on both the person with AD and caregivers[4-6].
- While past research focused on people with AD's quality of life, recent studies have shifted to understanding the caregiver's burden, showing increased distress and mental health issues correlating with AD severity[7,8].
- Most commonly experienced emotions reported by caregivers of individuals with mild cognitive impairment (MCI) were frustration, guilt, and anger, sense of loss and deprivation in their relationship with the person with AD.
- The CARE-eAD study aimed to assess the impact of informal caregiving for individuals with MCI in Spain.

Methods

Study Design and Participant Eligibility

- The CARE-eAD was a cross-sectional, non-interventional study (NIS) conducted at 19 dementia clinics in collaboration with the Spanish Confederation of Alzheimer's Disease (CEAFA).
- The study consisted in a single time point of data collection using a battery of questionnaires and tools during a consultation appointment for the person with MCI at the healthcare centre or with the physician, after signing the informed consent.
- Individuals providing informal care for people with a diagnosis of MCI (National Institute on Aging and the Alzheimer's Association clinical criteria) and a Global Deterioration (GDS) Scale score of 3 were included

Study endpoint

- The primary endpoint was to assess the strain of caregiving in caregivers of people with MCI using the Zarit Burden Interview (ZBI-22), with higher scores indicating greater distress or burden for the caregivers[9]
- A multivariate logistic regression analysis was conducted to determine the association between participants' characteristics and the impact of caregiving.
- The secondary endpoints are listed in **Figure 1**.

Figure 1. Secondary endpoints

Main secondary endpoints
- To assess the caregiver's mood using the Hospital Anxiety and Depression Scale (**HADS**).
- To assess the caregiver's feelings of hopelessness using the Beck Hopelessness Scale (**BHS**).
- To describe the caregiver's distress using the Neuropsychiatric Inventory (**NPI**) questionnaire.
- Caregiver's perception of stigma using the Affiliate Stigma Scale (**ASS**)

Other secondary endpoints
- Caregiver's feeling of being able to care for the person with MCI: the Short version of the Sense of Competence Questionnaire (**S-SCQ**).
- Caregiver-person with MCI relationship's quality:ng the Quality of the Caregiver-Patient Relationship Scale (**QCPR**).
- Caregiver's health-related quality of life using the Assessment of Quality of Life-6D (**AQoL-6D**).
- Caregiver's needs using the Managing Your Loved One's Health (**MYLOH**).
- Caregiver's resilience:14-Resilience Scale (**RS-14**).
- Caregiver's perception of adequacy of social support using the Duke-UNC Functional Social Support questionnaire (**FSSQ**).
- Caregiver's emotional exhaustion using one-single item of the Emotional Exhaustion (EE) dimension of the Maslach Burnout Inventory (**MBI**).
- Caregiver's effective and ineffective ways to cope with caring for patients with MCI using the Coping Orientation to Problems Experienced Inventory (**Brief-COPE**).
- To determine the working absenteeism and presenteeism among caregivers using the Value of Loss Productivity questionnaire (**VOLP**).
- To describe patients' involvement in everyday decision-making expressed by the caregiver using the 15-item Decision-Making Involvement Scale (**15-DMI**).

Results

- Of the 200 caregivers initially included in the study, 196 met the inclusion criteria and were evaluable participants for the present analysis.

Caregiver's characteristics

- The sociodemographic characteristics of the caregivers are shown in **Table 1**.

Table 1. Caregiver's characteristics

Characteristics	Caregivers (N=196)
Age (years), mean (SD)	63.5 (13.1)
Women, n (%)	123 (62.8)
Civil status*, n (%)	
Single	14 (7.2)
Married/with life partner	173 (89.2)
Divorced/widowed	7 (3.6)
Education level, n (%)	
Inferior to primary education	7 (3.6)
Primary education	49 (25.0)
Secondary education	35 (17.9)
Vocational education and training (VET)	33 (16.8)
Bachelor's degree	48 (24.5)
Master's degree and/or PhD	24 (12.2)
Years of education, mean (SD)	13 (4.7)
Working status, n (%)	
Active	65 (33.2)
Unemployed	18 (9.2)
Retired	108 (55.1)
Other	5 (2.6)
Work leaves due to caregiver activities on the last 6 months (N=65)	
Yes (active caregivers), n (%)	5 (7.7)
Number of days, mean (SD)	4.2 (2.0)

Abbreviations: SD, standard deviation. * Data unknown in 2 cases.

- Overall, 98% (n=192) of the caregivers were family members of the person with MCI, with partners (married/life partner) and the sons/ daughters representing over 68% (n=134) and 26% (n=51) of the caregivers, respectively (**Figure 2**).

Figure 2. Relationship between the caregiver and the person with MCI
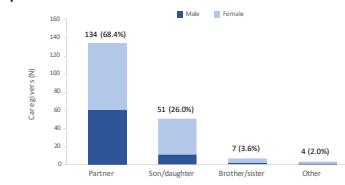
Percentages shown are according to the total of participants.

Person with MCI characteristics

- The Mini-Mental State Examination (MMSE) score of the people with MCI prior study inclusion was a mean of 25.2 (3.2), and the mean duration of the disease or cognitive impairment(n=196) was a mean of 2.9 (2.2) years (**Table 2**).

Table 2. Characteristics of people with MCI

Characteristics	People with MCI (N= 196)
Age (years), mean (SD)	72.9 (7.0)
Women, n (%)	111 (56.6)
Working status, n (%)	
Active	9 (4.6)
Unemployed	7 (3.6)
Retired	171 (87.2)
Other	9 (4.6)
GDS score = 3, n (%)	196 (100)
Mini-Mental State Examination (MMSE) score [1], mean (SD)	25.2 (3.2)
AD biomarkers analysis performed, n (%)	134 (68.4)
Disease/cognitive impairment duration, mean (SD)	2.9 (2.2)
Cholinesterase inhibitors therapy ongoing [2], n (%)	74 (37.8)

[1]Data available for 184 people, [2]Data available for 185 people, Abbreviations: GDS, Global Deterioration Scale; SD, standard deviation.

Level of burden experienced by caregivers

- The ZBI-22 questionnaire presented a mean (SD) global score of 22.3 (13.6). The score of each domain of this questionnaire is shown in **Figure 3**. Among caregivers, 59.7% (n=117) obtained a total ZBI-22 score ≥17, which indicates these subjects exhibited caregiving burden.

Figure 3. Scores of the ZBI-22 questionnaire
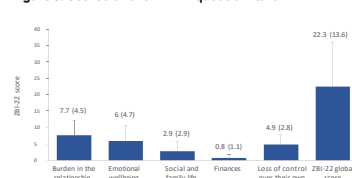
Data shown as mean (SD). Abbreviations: ZBI-22, Zarit Burden Interview

- Caregivers with ZBI-22 score ≥17 exhibited higher levels of anxiety and depressive symptoms, a more pronounced perception of stigma and hopelessness, increased avoidant coping strategies, lower resilience, poorer caregiver-individual relationships, and perceived inadequate social support compared to their counterparts (**Table 3**).
- Caregiver stress was associated with anxiety (p=0.017), stigma (p=0.007), emotional distress caused by neuropsychiatric symptoms (p=0.0001), and the need for a broader social support network (p<0.0001) in the multivariate analysis (**Table 3**).

Table 3. Bivariate and multivariate analyses to estimate the evaluated variables independently associated with perceived caregiving (ZBI-22 score≥17)

Independent covariates	Bivariate analysis ZBI-22 score ≥17	p-value	Multivariate analysis OR (95% CI)	p-value
QCPR score [1], mean (SD)	53.4 (9.2)	0.001*	-	-
QCPR score>42 [2], n (%)	103 (88.0)	0.006**	-	-
FSSQ score [1], mean (SD)				
Average	3.8 (0.7)	<0.001*	0.47 (0.36-0.64)	0.0001
RS-14 score [1], mean (SD)				
MBI score [3], n (%)				
Burnout score ≤2	89 (76.1)	0.016**	-	-
Burnout score ≥3	28 (23.9)	0.016**	-	-
ASS score [1], mean (SD)				
Sum	33.2 (8.2)	<0.001*	1.07 (1.02-1.12)	0.007
HADS score [1], mean (SD)				
Anxiety	8.4 (4.0)	<0.001*	1.13 (1.02-1.26)	0.017
Depression	5.4 (3.4)	<0.001*	-	-
Anxiety (score≥8) [4], n (%)	65 (55.6)	<0.001**	-	-
Depression (score≥8) [5], n (%)	28 (23.9)	0.028**	-	-
BHS score [1], mean (SD)	6.2 (3.9)	0.002*	-	-
BHS score ≥9 [6], n (%)	32 (27.4)	0.001**	-	-
NPI score [1], mean (SD)	7.5 (7.0)	<0.001*	1.15 (1.06-1.25)	0.0001
Brief-COPE score [1], mean (SD)				
Problem-focused score	2.8 (0.7)	0.148*	-	-
Emotion-focused score	2.2 (0.5)	0.199*	-	-
Avoidant score	1.7 (0.5)	0.016*	-	-

Questionnaires used to build the logistic regression were evaluated by both, total scores and individual domains.

[1] Continuous variable; [2] Reference category: QCPR score>42; [3] Reference category: MBI score≤2; [4] Reference category: HADS anxiety score<8; [5] Reference category: HADS depression score<8; [6] Reference category: BHS score<9.

*Mann-Whitney Test; **Chi-square test; Abbreviations: CI, confidence interval; OR, odd ratio; SD, standard deviation.

Caregiver's mood

- The mean (SD) of total HADS score for anxiety and depression was 7.1 (4.1) and 4.6 (3.4), respectively.
- For depression, 18.9% (n=37) of caregivers exhibited depression (**Figure 4A**) and nearly 6.1% (n=12) moderate or severe depression (**Figure 4B**).
- According to scoring scale, 41.8% (n=82) of caregivers showed presence of anxiety (**Figure 4A**) and 20.9% (n=41) exhibited moderate or severe anxiety (**Figure 4B**).

Figure 4. Presence of anxiety or depression in the caregivers

A

B
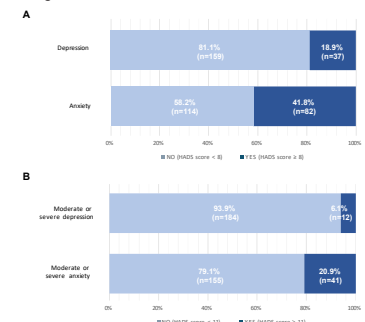
HADS scores ≥8 and HADS scores ≥11 were used as a threshold for indicating anxiety or depression (A) and moderate or severe anxiety or depression (B) in the caregivers, respectively.

Stigma

- The mean (SD) of total ASS score was 1.40 (0.34).
- 39.3% (n=77) of caregivers perceived some level of stigma, with AAS score>31 (sum of the 22 items) (**Figure 5**).
- The levels of caregiving burden, resilience, hopeless-ness and avoidant coping style were independently associated with this caregiver's perception of stigma.

Perception of affiliate stigma			N
No (score≤31), n (%)			119 (60.7)
Yes (score>31), n (%)			77 (39.3)
Domain	**Mean**	**S.D.**	**N**
Cognitive	1.21	0.28	196
Affect	1.71	0.56	196
Behavior	1.30	0.36	196
Total score ASS	1.40	0.34	196

Caregiver's distress

- The most frequent behavioural disturbances were dysphoria/depression (44.4%, n=87), apathy (39.3%, n=77) and irritability (33.2%, n=65). On the contrary, the less frequent were hallucinations (4.1%, n=8) and delusions (8.7%, n=17).
- The total NPI score was a mean (SD) of 7.4 (6.4). The behavioural problems that caused more distress for caregivers were anxiety, dysphoria/depression, and agitation/aggression (**Figure 6**).

Figure 6. Distress scores of the caregivers who are experiencing the patient's behaviour problems
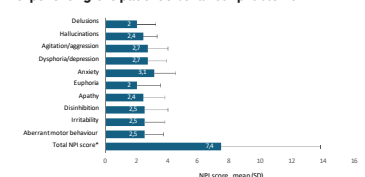
*Score taking into account the patients who performed all 10 activities (N=146).
Abbreviations: NPI, Neuropsychiatric Inventory; SD, standard deviation

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Conflicts of interest

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