Perspectives on disease burden among informal care partners of people with mild cognitive impairment or dementia due to Alzheimer's disease: a real-world survey.

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OBJECTIVE

- To evaluate the characteristics of informal care partners (CPs) of patients with mild cognitive impairment (MCI) or dementia due to Alzheimer's disease (AD), and the level of burden experienced, as reported by CPs.
- To explore associations between different activities of daily living (ADLs) domains and CPs-reported burden.

CONCLUSION

- Patient care falls primarily on the family. ZBI results show that informal CPs experience a mild-to-moderate care burden.
- Furthermore, differences in the mean (SD) ZBI scores were observed between CPs of patients with MCI/Mild dementia due to AD who require assistance with at least one ADL and those who do not. These differences were also evident among CPs of patients with Moderate/Severe dementia due to AD. This suggests that the level of assistance with ADLs may have an impact on the CPs' burden irrespective of disease severity.
- Consequently, future studies could help identify areas of struggle or need for informal CPs, so that relief strategies can be implemented, thus benefitting both CPs and patients.

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STUDY DESIGN

- Data were drawn from the Adelphi Real World AD Disease Specific Programme™ (DSP), a cross-sectional survey with elements of retrospective data collection from physicians and their patients with MCI or dementia due to AD conducted in France, Germany, Italy, Spain, the United Kingdom, the United States, and Japan from December 2022 to March 2024.
- Physicians completed patient record forms for their next nine consecutively consulting patients, capturing information on patient's disease severity.
- CPs who attended the consultation with the patient were invited to complete a self-completion form, capturing their sociodemographic information and experiences caring for the patient, including level of burden experienced via Zarit Burden Interview.
- The DSP methodology have been previously published, validated[6-8], and found to be consistent over time[9].
- The Zarit Burden Interview (ZBI) is composed of a 22-item questionnaire aiming to assess the level of burden experienced by CPs. It includes domains covering burden in the relationship; emotional well-being; social and family life; finances; and loss of control over one's life (0–88 scale, higher scores indicate greater burden)[10].
- The ZBI score for CPs was also stratified by the domains of ADLs in which the patients require assistance: basic (e.g., eating, walking), communication (e.g., read books, make appointments), domestic (e.g., cooking, cleaning), outside (e.g., travelling, shopping).
- Analyses were descriptive and sample size varied among variables, as there was no imputation of missing data. Analyses were summarized as percentages or mean (standard deviation [SD]).

BACKGROUND

- AD is a neurodegenerative disease characterized by cognitive impairment and behavioral changes that worsen as the disease progresses, ultimately impacting patients' ability to perform ADLs[1]. It is foreseen that by 2050, global prevalence will undergo a 3-fold increase[2].
- As the disease progresses, patients experience increasing decline in cognitive performance and functioning requiring increasing assistance[3].
- Greater impairment in patient functionality has been found to be associated with increased caregiver burden[4] and higher societal cost[5]. Little research, however, has looked at the different categories of ADLs that drive such issues.

RESULT

- Overall, 768 CPs of patients (France n=88; Germany n=155; Italy n=68; Spain n=176; UK n=37; US n=99; Japan n=145) completed the questionnaire. Their sociodemographic characteristics are summarized in Table 1.
- Of those CPs, 712 reported a mean (SD) ZBI score of 36.5 (16.5), on aspects including feeling stressed, financial concerns, feeling they do not have enough time for themselves.

Table 1: Care partners sociodemographic characteristics.

Characteristic	CPs answering the question (N=768)
Age, mean (SD)	[n=757] 61.1 (14.2)
Female, n (%)	[n=763] 501 (65.7)
Relationship status, n (%)	[n=756]
Married/ Cohabiting	584 (77.2)
Single/ Never Married	103 (13.6)
Divorce/Separated	47 (6.2)
Employment status, n (%)	[n=747]
Retired	256 (34.3)
Working full-time	222 (29.7)
Working part-time	113 (15.1)
Relationship with patient, n (%)	[n=758]
Child	321 (42.3)
Partner	315 (41.6)
Living with patient (yes), n (%)	[n=756] 501 (66.3)
Hours spent caregiving weekly, mean (SD)	[n=377] 64.8 (60.2)

Abbreviations: AD, Alzheimer's disease; CP, care partners; MCI, mild cognitive impairment; n, number; N, total number of participants; SD, standard deviation; UK, United Kingdom; US, United States; ZBI, Zarit Burden Interview..

Key Result

- Of 358 patients with MCI/Mild dementia due to AD, whose care partner provided a ZBI score,181 needed help with ≥1 basic ADL, 302 with ≥1 domestic ADL, 181 with ≥1 communication ADL, and 240 with ≥1 outside ADL.
- Of the 340 patients with Moderate/Severe dementia due to AD, whose care partner provided a ZBI score, 289 needed help with ≥1 basic ADL, 313 needed help with ≥1 domestic ADL, 244 needed help with ≥1 communication ADL, and 291 needed help with ≥1 outside ADL (Table 2).

Table 2. Zarit Burden Interview score of care partners stratified by activities of daily living requiring assistance.

	MCI/Mild dementia due to AD [N=358]		Moderate/Severe dementia due to AD [N=340]	
Zarit Burden Interview score, mean (SD) for activity category	No help with activities required	Help with at least one activity required	No help with activities required	Help with at least one activity required
Basic	31.6 (17.1) [N= 177]	36.7 (16.7) [N= 181]	35.7 (12.4) [N= 51]	39.5 (16.0) [N= 289]
Domestic	30.8 (16.3) [N=56]	34.8 (17.1) [N= 302]	39.9 (15.7) [N= 27]	38.8 (15.6) [N= 313]
Communications	31.3 (17.0) [N=177]	37.0 (16.7) [N= 181]	35.5 (15.4) [N= 96]	40.3 (15.5) [N= 244]
Outside	31.7 (17.0) [N= 118]	35.4 (17.0) [N= 240]	39.7 (14.7) [N= 49]	38.8 (15.7) [N= 291]

- The CPs of patients with MCI/Mild dementia due to AD who required help with at least 1 basic or communication ADL reported a mean (SD) ZBI score of 36.7 (16.7) and 37.0 (16.7), respectively, and those caring for patients with MCI/Mild dementia due to AD who do not require help with basic or communication ADLs reported a mean (SD) ZBI score of 31.6 (17.1) and 31.3 (17.0), respectively.
- The CPs of patients with Moderate/severe dementia due to AD who do not require help with domestic or outside ADLs reported a mean (SD) ZBI score of 39.9 (15.7) and 39.7 (14.7), respectively, while CPs of patients with Moderate/Severe dementia due to AD who required help with at least 1 domestic or outside ADLs reported a mean (SD) ZBI score of 38.8 (15.6) and 38.8 (15.7), respectively.

Limitations

- The DSP is based on a pseudo-random sample of physicians or patients. While minimal inclusion criteria governed the selection of participating physicians, participation was influenced by their willingness to complete the survey.
- Participating patients may not reflect the general Alzheimer Disease population since the DSP only includes patients and their care partners who are consulting with a physician. This means that patients and care partners who consult more frequently have a higher likelihood of being included.
- Recall bias, a common limitation of surveys, might have affected responses of both physicians and care partners.
- The cross-sectional design of this survey prevented any conclusions about causal relationships.

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