

# Supplementary Material

## A Literature Review on the Burden of Alzheimer's Disease on Care Partners

### Supplementary Table 1. Electronic search strings

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Systematic review 1: Burden of AD on care partners including QoL and impact on work, school, and everyday life, including absenteeism, presenteeism, and humanistic and economic burden of AD

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(((((“Alzheimer Disease”[MeSH Terms] OR (“alzheimer”[All Fields] AND “disease”[All Fields]) OR “Alzheimer Disease”[All Fields] OR (“alzheimer s”[All Fields] AND “disease”[All Fields]) OR “alzheimer s disease”[All Fields] OR “Alzheimer Disease”[MeSH Terms]) AND (“quality of life”[MeSH Terms] OR (“quality”[All Fields] AND “life”[All Fields]) OR “quality of life”[All Fields] OR “burden”[All Fields] OR “QoL”[All Fields] OR “PROMs”[All Fields] OR “patient-reported outcome”[All Fields] OR “patient-reported outcomes”[All Fields]) AND (“caregiver s”[All Fields] OR “caregivers”[MeSH Terms] OR “caregivers”[All Fields] OR “caregiver”[All Fields] OR “caregiving”[All Fields] OR (“caregivers”[Mesh Terms] OR “caregivers”[All Fields] OR “carer”[All Fields] OR “carers”[All Fields] OR “carer s”[All Fields]))) NOT “Review”[Publication Type]) NOT “systematic review”[Title/Abstract]) NOT “meta-analysis”[Title/Abstract]) AND “English”[Language] AND 2010/01/01:3000/12/31[Date - Publication]

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Systematic reviews 2 and 3: Cost of AD (indirect and direct) and healthcare resource use\*

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(((((“Alzheimer Disease”[MeSH Terms] OR (“alzheimer”[All Fields] AND “disease”[All Fields]) OR “Alzheimer Disease”[All Fields] OR (“alzheimer s”[All Fields] AND “disease”[All Fields]) OR “alzheimer s disease”[All Fields] OR “Alzheimer Disease”[MeSH Terms]) AND (“economics”[MeSH Subheading] OR “economics”[All Fields] OR “cost”[All Fields] OR “costs and cost analysis”[MeSH Terms] OR (“costs”[All Fields] AND “cost”[All Fields] AND “analysis”[All Fields]) OR “costs and cost analysis”[All Fields] OR “resource utilisation”[All Fields] OR “economic burden”[All Fields] OR “expenses”[All Fields] OR “out of pocket”[All Fields])))) NOT “Review”[Publication Type]) NOT “systematic review”[Title/Abstract]) NOT “meta-analysis”[Title/Abstract]) AND “English”[Language] AND 2010/01/01:3000/12/31[Date - Publication]

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\*The same search strings were used for the cost and healthcare resource use reviews, but data extraction was performed separately for each review.

AD, Alzheimer's disease; QoL, quality of life.

**Supplementary Table 2.** Supplementary targeted searches: Search terms

Disease term	Population terms	Outcome terms
Alzheimer's disease	Care partner Caregiver Carer Family member Spouse	Quality of life Health-related quality of life Utility score Impact Burden Health Health status Comorbidities Economic impact Economic burden Indirect cost Societal cost Healthcare resource use

**Supplementary Table 3. Supplementary targeted searches: Eligibility criteria**

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Patient population	Care partners of individuals with Alzheimer’s disease (from mild cognitive impairment to severe dementia of the Alzheimer’s type)
Intervention/Comparator	None
Outcomes	<ul style="list-style-type: none"><li>• Care partner health, including comorbidities</li><li>• Care partner quality of life, including both quantitative and qualitative assessments</li><li>• Economic impact on care partners, including healthcare resource use</li></ul>
Study design	Observational/RWE studies will be included Interventional studies will be excluded
Reference types	Primary manuscripts and congress publications, systematic literature reviews and meta-analyses will be included Exclusion: animal/ <i>in vitro</i> studies, case reports and case series, and review articles
Date restrictions	2021–2022
Language restrictions	English language
Country	No restriction

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RWE, real-world evidence

**Supplementary Table 4.** Supplementary targeted searches: Search terms

Study characteristic	Number of studies identified in SLR (references)	Number of studies identified in supplementary searches (references)
<b>Geographic origin</b>		
Europe	48 [1-48]	11 [49-59]
Asia	29 [60-88]	8 [76, 89-95]
USA	24 [96-119]	8 [120-127]
Canada	3 [128-130]	1 [131]
Australia	2 [132, 133]	0
South America	6 [134-139]	2 [140, 141]
<b>Study design</b>		
Cross-sectional	56 [1, 8, 9, 11, 12, 15, 16, 27, 28, 31, 40, 45, 48, 60, 61, 64-66, 68, 71-75, 77-82, 84, 85, 87, 88, 96, 97, 99, 102, 104, 105, 108, 110, 112, 115-117, 128, 129, 133, 134, 136, 137, 139, 142-144]	28 [49, 50, 52-59, 89-95, 120, 122-127, 131, 140, 141, 145]
Interventional controlled	7 [5, 6, 13, 63, 86, 135, 138, 146]	0
Longitudinal observational	28 [2, 4, 7, 10, 14, 18, 19, 22, 25, 26, 29, 30, 32, 33, 36, 39, 42-44, 46, 47, 62, 68, 76, 103, 106, 109, 111, 113, 114, 130, 132, 147]	4 [51, 76, 121, 148]
SLR, systematic literature review		

**Supplementary Table 5. Key studies addressing each research question**

Research question	First author and year	Country, design	Setting	Number of care partners of individuals with AD <sup>a</sup>	Follow-up	Care partner outcomes
1) How does caring for an individual with AD affect care partners' QoL?	Montgomery et al. (2018) [75]	Japan, cross-sectional	Community	300	NA	EQ-5D PHQ-9
	Liao et al. (2020) [72]	China, cross-sectional	Hospital, care home, and community	206	NA	WHOQOL-BREF ZBI SSRS
	Froelich et al. (2021) [148] <sup>b</sup>	Multinational (Germany, Spain, UK), prospective observational	Community	616	Up to 24 months	EQ-5D ZBI Time spent caregiving
	Tentorio et al. (2020) [42] <sup>b</sup>	Italy, prospective observational	NR	69	1 year	RSS BDI NPI sub-item 'stress' STAI-Y CBI
	Nakanishi et al. (2021) [76] <sup>b</sup>	Japan, prospective observational	Community	553	18 months	ZBI Informal care costs Time spent caregiving
	Liu et al. (2017) [73] <sup>c</sup>	China, cross-sectional	Outpatient clinic	309	NA	PHQ-9 GAD-7 PSQI ZBI
2) How does caring for an individual with AD affect care partners' physical health?	Okuda et al. (2019) [78] <sup>c</sup>	Japan, cross-sectional	NR	496	NA	BIC-11 PSQI PHQ-9 SF-12 v2
	Athanasiadou et al. (2021) [49] <sup>c</sup>	Greece, cross-sectional	Community (81.4%); other NR	60	NA	CWSv2
	Montgomery et al. (2018) [75] Socci et al. (2021) [36]	Japan, cross-sectional Italy, retrospective observational	Community Community	300 146	NA 12 months	EQ-5D PHQ-9 CBI HADS SF-12
3) How does caring for an individual with AD affect care partners' health?	Wimo et al. (2013) [47]	Multinational (France, Germany, UK), prospective observational	Community	1497	None (baseline data)	Informal care costs Healthcare resource use

	cost burden and healthcare resource use?	Nakanishi et al. (2020) [147]	Japan, prospective observational	Community	553	None (baseline data)	Informal care costs Healthcare resource use Time for ADL
		Olazarán et al. (2017) [25]	Spain, prospective observational	Community	380	6 months	Informal care costs Healthcare resource use
4)	To what extent do care partners of people with AD experience work impairment?	Ashrafizadeh et al. (2021) [89]	Iran, cross-sectional	Community	11	NA	Bespoke interview on caregiving experience
		Athanasiadou et al. (2021) [49] <sup>c</sup>	Greece, cross-sectional	Community (81.4%); other NR	60	NA	CWSv2
5)	What aspects of caregiving contribute to informal care costs?	Ikeda et al. (2021) [67]	Japan, modelling study	Japanese population	~2.588 million	1 year	Productivity loss
		Olazarán et al. (2017) [25]	Spain, prospective observational	Community	380	6 months	Informal care costs Healthcare resource use
6)	What is the relationship between the patient's AD severity and the impacts on the care partner, in terms of their health, QoL, costs, and resource use?	Montgomery et al. (2018) [75]	Japan, cross-sectional	Community	300	NA	EQ-5D PHQ-9
		Yin et al. (2021) [84]	China, cross-sectional	Hospital	300	NA	ZBI
		Bergvall et al. (2011) [142]	Multinational (Spain, Sweden, UK, USA), cross-sectional	Community	866	NA	Caregiver time ZBI
		Küçükgüçlü et al. (2017) [70]	Turkey, cross-sectional	Outpatient clinic	90	NA	CBI
		Reed et al. (2017) [32]	Multinational (France, Germany, UK), prospective observational	Community	1495	18 months	ZBI EQ-5D Informal care costs HCRU Caregiver time
	Sinha et al. (2017) [79]	India, cross-sectional	Outpatient clinic	32	NA	ZBI GHQ	
7)	To what extent does informal caregiving contribute to the total	Wimo et al. (2013) [47]	Multinational (France, Germany, UK), prospective observational	Community	1497	None (baseline data)	Informal care costs Healthcare resource use

societal costs associated with AD?	Kongpakwattana et al. (2019) [69]	Thailand, retrospective observational with cross-sectional interview	Hospital	148	6 months	Informal care costs Caregiver time
	Yu et al. (2021) [87]	China, cross-sectional	Hospital	NR	NA	Informal care costs

<sup>a</sup>Only data focusing exclusively on care partners of individuals with AD are included in this table; <sup>b</sup>Study reports burden instrument outcomes – does not map strictly to this research question but included due to volume of evidence identified; <sup>c</sup>Study reports mental health outcomes – does not map strictly to this research question but included due to volume of evidence identified.

AD, Alzheimer’s disease; ADL, Activities of Daily Living; CWSv2, Carer Well-Being and Support Questionnaire version 2; GHQ, General Health Questionnaire; HCRU, healthcare resource use; NA, not applicable; NR, not reported; RSS, Relative Stress Scale; SSRS, Social Support Rating Scale

**Supplementary Table 6. Instruments measuring care partner burden**

Instrument	Overview
Burden Index of Caregivers (BIC)	The BIC comprises 11 items covering 5 domains and was designed to reflect circumstances faced by caregivers of patients with intractable neurological conditions in Japan [149]
9-item Patient Health Questionnaire (PHQ-9)	The PHQ-9 is used to measure depression severity. Each of the 9 statements is rated from 0 (not at all) to 3 (nearly every day), with scores of 5, 10, 15, and 20 representing mild, moderate, moderately severe, and severe depression, respectively [150]
Pittsburgh Sleep Quality Index (PSQI)	The PSQI measures sleep quality and disturbances over a 1-month time interval. Nineteen individual items generate seven "component" scores; the sum of scores for these seven components yields one global score, ranging from 0 to 21 (higher scores indicate poorer sleep quality) [151]
EQ-5D	The EQ-5D is a widely used instrument for measuring health-related quality of life across a range of medical conditions and populations [152]
Delirium Burden instrument for care partners (DEL-B-C)	The DEL-B-C contains 8 questions pertaining to experience as a care partner for a patient with delirium, and is measured on a 0–40-point scale (higher scores indicate higher burden) [153]
World Health Organization Quality of Life Questionnaire (WHOQOL)	The WHOQOL is a cross-cultural quality of life assessment tool [154]
12-Item Short-Form Health Survey version 2 (SF-12v2)	The SF-12v2 is a generic 12-item physical and mental health questionnaire covering 8 domains; each health domain score contributes to the Physical Component Summary (PCS) and Mental Component Summary (MCS) scores [155]
Caregiver Activity Survey	The Caregiver Activity Survey measures time spent caring for individuals with AD, and consists of 6 items (communicating with the person, using transportation, eating, dressing, looking after one's appearance and supervising the person) [156]

AD, Alzheimer's disease



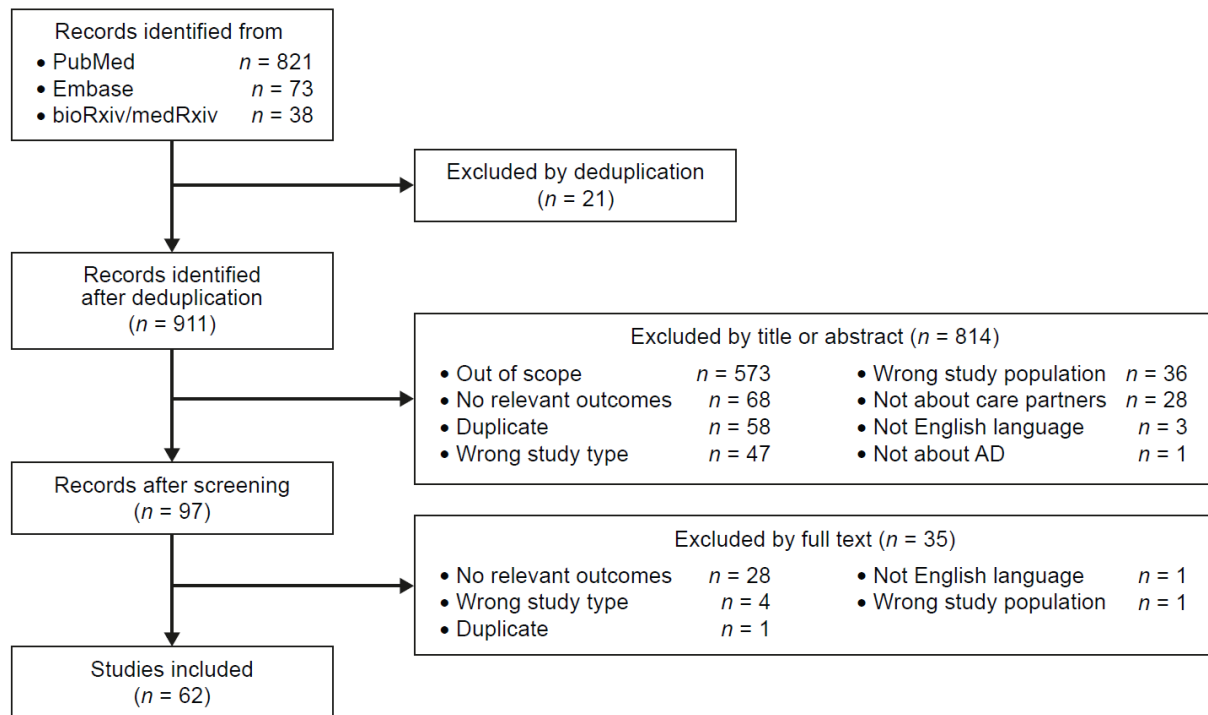
**Supplementary Table 7. Monthly cost of caretaking was similar across countries and studies**

Mean cost per month, Euros	Disease severity*		
	Mild AD dementia	Moderate AD dementia	Severe AD dementia
High	1050 (Spain) [25]	1329 (Germany) [47]	2376 (Germany) [47]
Low	643 (Germany) [47]	804 (France) [47]	1338 <sup>†</sup> (Japan) [76]

\*Based on Mini-Mental State Examination scores of 21–26 (mild), 15–20 (moderate), and < 15 (moderately severe to severe); <sup>†</sup>Value converted from USD to Euros.

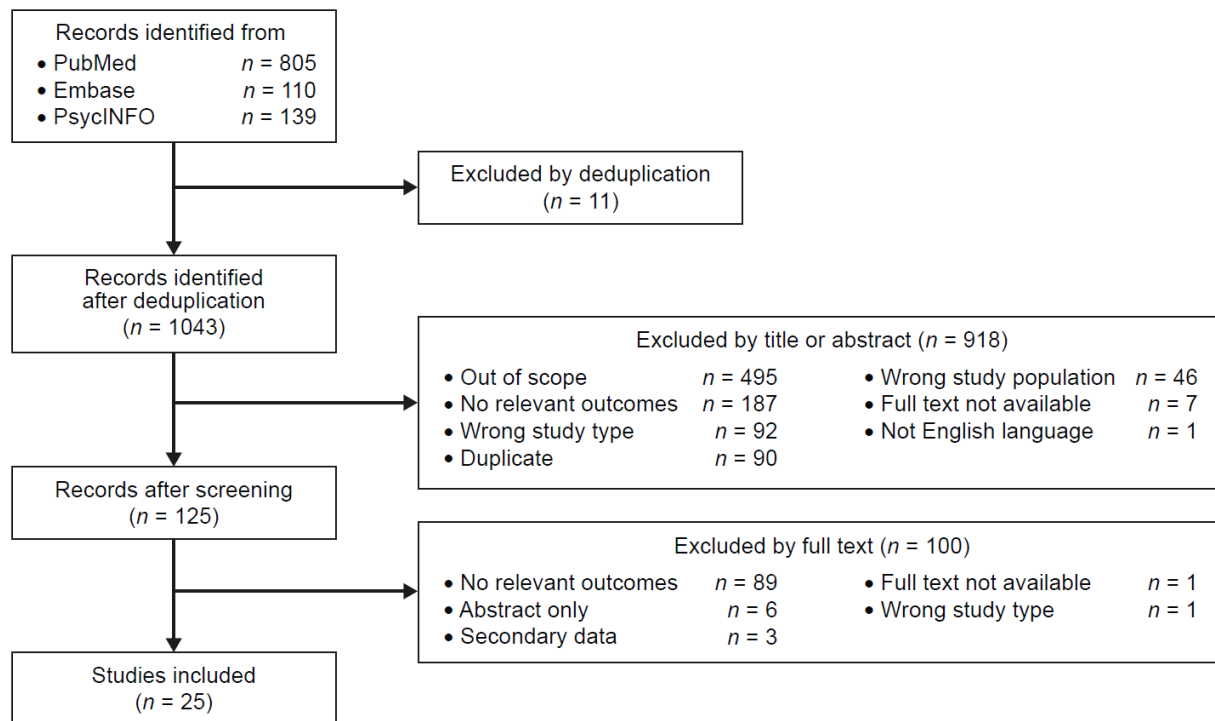
AD, Alzheimer's disease; USD, US dollars

**Supplementary Figure 1. PRISMA flow diagram: Care partner burden SLR.**



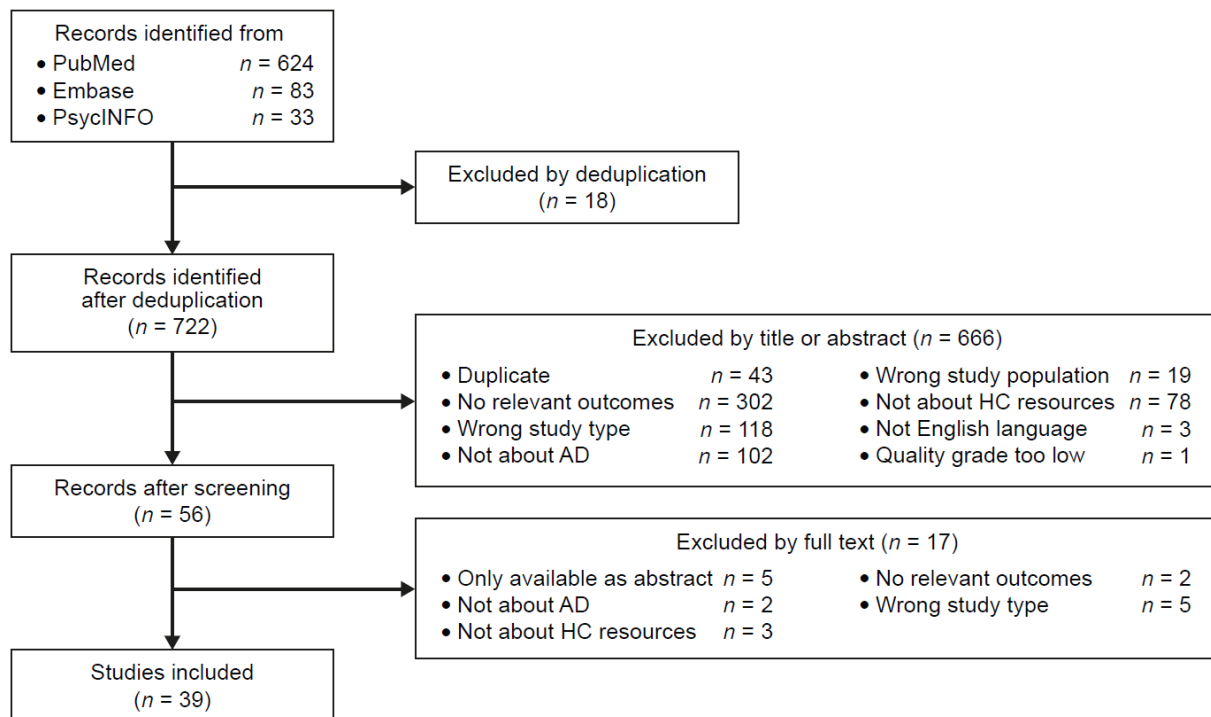
AD, Alzheimer’s disease, SLR, systematic literature review

**Supplementary Figure 2. PRISMA flow diagram: Cost burden SLR.**



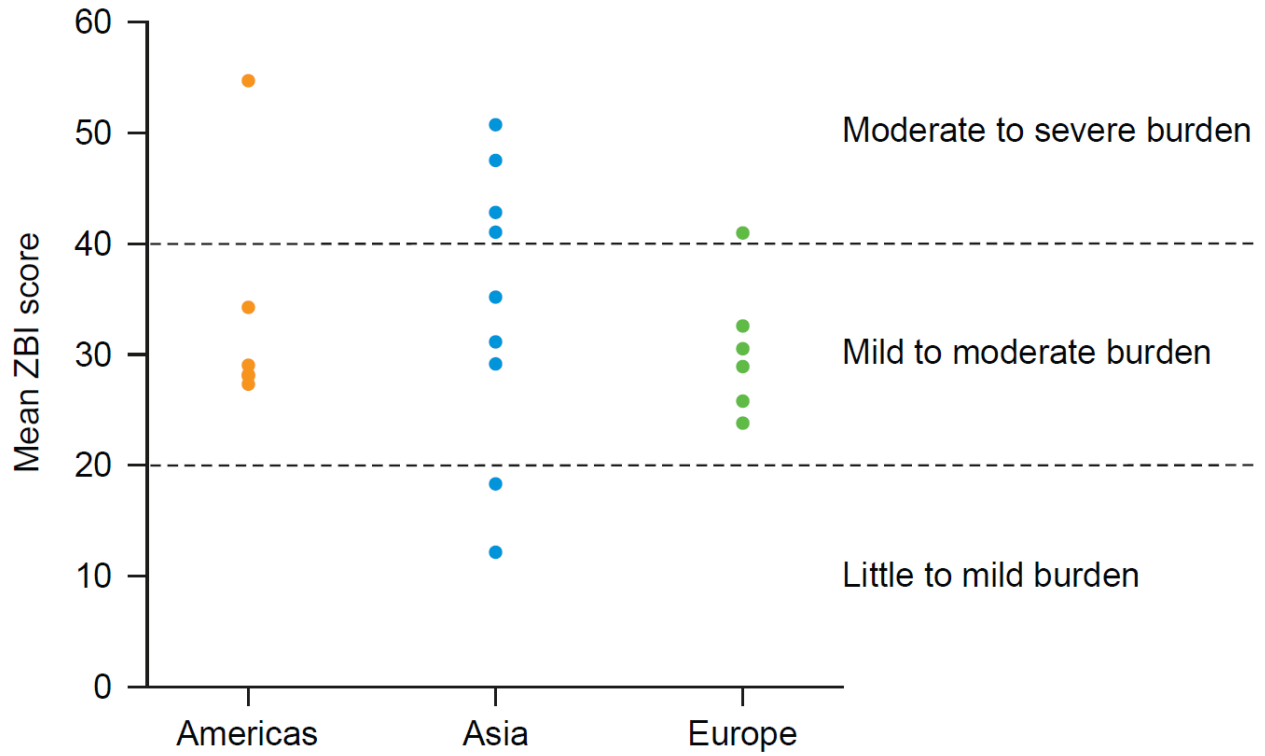
SLR, systematic literature review

**Supplementary Figure 3.** PRISMA flow diagram: Healthcare resource use SLR.



AD, Alzheimer’s disease, HC, healthcare; SLR, systematic literature review

**Supplementary Figure 4.** Distribution of mean ZBI-22 scores.



Each data point represents one study.

ZBI, Zarit Burden Interview; ZBI-22, 22-item Zarit Burden Interview

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