



OPEN Caregiver burden of Alzheimer's disease among informal caregivers: a cross-sectional study in Malaysia

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Alzheimer's disease (AD) not only impacts the patients but substantially informal caregivers in terms of physical and psychological burden. This study aims to determine the burden level of informal caregivers of patients with different stages of AD and use of special accommodation (SpA) along with its predictors. A cross-sectional study was conducted by interviewing AD patients and informal caregivers recruited from 4 tertiary hospitals. Zarit Burden Interview (ZBI) was used to estimate caregivers' burden. The analysis categorized informal caregivers of AD patients into two groups based on the use of SpA. Multivariable linear regression was employed to identify potential determinants of subjective caregiver burden. As a result, caregivers' burden experienced by informal caregivers of severe community-dwelling AD patients was significantly higher ($p=0.024$) than those with special accommodation. As AD advanced, caregivers' burden was elevated significantly ($p=0.021$) from mild to severe AD among community-dwelling patients. In multivariable analysis, severe AD (standardised $\beta=0.187$, $p=0.047$ vs. mild AD) and spousal relationship (standardised $\beta=0.241$, $p=0.026$ vs. other relationships) were found to be significant factors in predicting caregivers' burden. Hence, the physical and social needs of informal caregivers must not be overlooked. Severe AD significantly increased caregiver burden in community dwelling patients. Spousal caregivers report a higher perceived burden compared to caregivers with other relationships. Policymakers need to recognize and address the substantial demands placed on informal caregivers by providing essential social support. Special accommodation could alleviate the burden on informal caregivers, particularly those caring for patients with severe AD.

Alzheimer's disease and related dementia (ADRD) has possessed a significant challenge towards the society particularly the elderly population¹. Followed by phenomenon of population ageing, patients with dementia is expected to reach 74.7 million in 2030 and further increased to 132 million in 2050². Apart from cognitive decline in multiple domains, deterioration in performing ADL and occurrence of behavioral and psychological symptoms of dementia (BPSD) are more disturbing towards both patients and informal caregivers³⁻⁵. As the level of dependency increases along with disease severity, informal caregivers devoted more time in daily needs and supervision of dementia patients^{6,7}. With that, multiple studies were published to describe caregiver's burden in providing dementia care⁸⁻¹².

Caregiver burden (CGB) is defined as the multifaceted stress perceived by the caregiver from looking after a family member or loved ones over time¹³. Most of the informal caregivers consist of first-degree relatives who has greater family bonding with patients such as spouses, children, siblings and cousins¹⁴. By spending time monitoring the welfare of dementia patients, the needs of informal caregivers were often neglected in terms of physical or emotional well-being¹⁵. This could be evidenced by Bertrand et al. study where CGB was higher in those who took care of dementia patients compared to older people without dementia¹⁶. Differences in such self-rated burden scores were more evident in working individuals due to greater work productivity loss¹⁷. Such scenario could further associate with higher depression and anxiety levels in informal caregivers apart from physical fatigue¹⁸⁻²¹.

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Multiple factors were found to be predictive in changes of CGB in patients with dementia such as deterioration in disease severity, cognitive function, ADL, BPSD, depression and agitation^{9,10,15,22,23}. A cross-sectional study in South Korea revealed that the ability to perform ADL was found to be a predictive factor in assessing caregivers' burden²⁴. Such scenario occurred due to the surge of time spent in providing daily assistance towards patient with dementia, which indirectly affected their daily productivity^{22,25}. Similar findings were found in different countries^{15,26–28}. When time spent on patients with AD is inadequate to provide optimized care, this could indirectly increase formal healthcare utilization and result into premature institutionalization^{23,29–31}. Besides, BPSD were also widely discussed as one significant predictor in CGB^{11,15,21,28}. With agitation, it raises difficulty in providing daily care tasks to patients with dementia such as bathing, toileting, and eating where they tend to have resistive movements towards informal caregivers^{11,32}. Not only that, depressive patients with dementia presents huge challenge towards informal caregivers in understanding their needs which translates to high CGB^{15,24}. Such behavioral deficits requires continuous attention and supervision before causing harm to themselves or people around them⁵.

Caregiver factors should not be neglected in exploring associations with caregivers' burden in Alzheimer's care. Findings from several studies showed that female caregivers recorded a higher caregiver burden in patients with AD care either their spouse or adult-daughter^{5,14,15,28}. If there is only sole caregiver who lives with patients with AD, CGB increases particularly physical aspects^{7,14,33}. Besides, findings regarding caregivers age as a contributing factor of caregiver's burden were inconsistent^{5,7,24,32,34}. Nevertheless, it could be an indirect influence towards caregivers burden particularly spousal caregivers as they may experience physical frailty or other medical comorbidities^{5,35}. Depressive symptoms in caregivers could also affect the burden scores as presented in a 18-month longitudinal study in Taiwan²¹. Similar findings could be explained as the lack of time in personal activities and routine adjustment to cater for functional needs of patients with AD^{14,17}. In Asia, burden scores from caregivers were lower than that in Western countries. Such scenario was due to most caregivers would prefer to take up the main responsibility as a fulfillment of filial piety of society particularly those who were influenced by Confucianism^{36,37}.

Due to the progressive nature of this disorder, increased demand on health and social care are anticipated which mostly rely on informal caregivers. This leads to rising concerns about increased opportunity cost and well-being losses among informal caregivers¹⁷. To alleviate CGB, informal caregivers seek assistance from formal care services or special accommodation (SpA) care such as daycare, respite care, nursing home and dementia-specific institutionalization. Despite large expenditure incurred in obtaining SpA care, such practice was associated with better well-being of both informal caregivers and AD patients particularly those with severe AD^{17,27}. For instance, nature-based activities in SpA could bring relaxation and reduce agitation among dementia patients such as caring for indoor plants³⁸. In viewpoint of caregivers, transition of care to SpA could reduce their burden level whether it is temporary or permanent³⁹. As CGB is highly correlated with quality of life (QoL), SpA serves as a viable option in care transition to reduce caregiving burden and improve their own QoL^{39,40}.

Based on United Nations, Malaysia, as an upper-middle income country, is emerging as an aging nation in 2023 with 7.4% of the population aged 60 years old and above. In view of this, there are rising healthcare concerns of geriatric diseases including AD^{41–43}. Due to its progressive nature, informal caregiver plays significant role to accommodate patient deficits in life independence⁷. With that, their physical and mental aspect as an informal caregiver should be concerned. To understand caregivers' burden in Alzheimer's care among local population in Malaysia, Razi et al. systematically reviewed 7 local articles that were published between 2000 and 2020. Moderate to high levels of CGB was recorded among caregivers of patients with dementia in Malaysia, which was explained by possible inadequate resources in social support⁴⁴. Such situation does not only affect Asia Pacific but other regions as well^{5,33,45}. However, the author disclosed that use of Caregiver Strain Index (CSI) instrument in those articles may limit the accuracy of study comparison. Zarit Burden Interview (ZBI) instrument were mentioned in the review as a more comprehensive tool in measuring CGB⁴⁴. Not only that, previous local studies of dementia patients did not report relationship between disease severity and caregiver burden. As it was reported positive relationship between disease severity and caregiver burden in many studies^{7,14,21,30}, it is important to explore the level of caregiver burden in different stages of AD in Malaysia.

Although many studies reported CGB in dementia, they were conducted from developed countries with government-funded dementia care services and caregiver support^{14,15}. More evidences from low-middle income countries (LMICs) are essential in making meaningful comparison of caregiver burden in AD and dementia care. Malaysia, as a multiethnic country, may have own unique perceptions and cultural norms in such issues. Due to cultural factors, first-degree relatives particularly children would attain their filial piety by taking care of their parents instead of external assistances^{23,46}. High stress in providing daily assistance might cause potential barriers to informal caregivers to achieve life satisfaction by balancing their own life and beloved ones⁴⁷. With that, assessment of informal CGB is important to understand the impact of unpaid caregiving tasks towards informal caregivers in the society⁴⁸. By using ZBI, this paper aims to determine the CGB of informal caregivers among patients with different AD severities. Besides, the secondary objective is to investigate potential differences in CGB among informal caregivers between community-dwelling AD patients and those utilized SpA care.

Methodology

Study design

A cross-sectional study was conducted in four tertiary hospitals in Malaysia namely Hospital Pulau Pinang (HPP), Hospital Seberang Jaya (HSJ), Hospital Kuala Lumpur (HKL) and Sarawak Heart Centre (PJS) using non-probability convenience sampling. By using the Scalex SP calculator, the sample size was calculated using the prevalence approach⁴⁹. With an absolute precision of $\pm 5\%$ and a potential attrition of 10%, the required sample size was 134 with the expected dementia prevalence of 8.5% from the National Health Morbidity Survey 2018^{49,50}. During outpatient visits in psychiatry or geriatric clinics, eligible patients and informal caregivers were

approached for study participation. Recruitment was carried out by specialists or the principal investigators on site at the selected study sites from 1 January to 31 December 2023. This study has been designed adhering to World Medical Association (WMA) declaration of Helsinki⁵¹ and ethically approved by Medical Research Ethics Committee Malaysia (MREC) [21-02014-VCP (IIR)].

Participants

Patients with AD aged 65 years old and above with a confirmed diagnosis of AD by specialists according to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) along with their informal caregiver were eligible to the study⁵². Informal caregiver is defined as the primary caregiver who is responsible to the ADL of patients with AD without getting paid in this study, referring to previous literature^{17,53–55}. They should be above 18 years old and have taken care of patients with AD for a minimum of 3 months to be included in the study.

Data collection

An interviewer-led session was conducted using structured questionnaire to collect data regarding socio-demographics of both patients with AD and informal caregivers, time spent in informal care and ZBI for caregivers' burden assessment. Written informed consent was obtained from all participants prior to the start of the study. Patient information was retrieved from patient medical records such as age, gender, disease severity, Mini-Mental State Examination (MMSE) score and presence of BPSD. DSM 5th Edition was referred to patient categorisation based on cognitive and functional abilities, which the full details are available in the manual⁵².

A structured questionnaire with adaptations of the Resource Use in Dementia (RUD) instrument was used to collect informal caregiver information such as age, gender, relationship to the patient, marital status, cohabitation, number of informal caregivers involved, employment status, medical comorbidities, use of SpA, type of ADL assistance provided, time spent on informal care in last 30 days and gross monthly salary in the interview⁵⁴. In this study, SpA care refers to use of formal caregiving services provided by trained personnel including nursing care, daycare and paid caregivers. To differentiate with those who did not utilize any form of formal care services such as nursing care or residential aged care institutions, the term “community dwelling AD patients” was used to describe those without any SpA care⁵³. Regarding the ADL, it was categorised into basic ADL (such as eating, dressing, grooming, walking and bathing) and instrumental ADL (such as shopping, housekeeping, transportation, managing medication and finance) in the questionnaire^{54,56}. The monthly income level was categorised into three levels which are lower than average (<RM3212), above average (RM3213–RM6423) and far above average (\geq RM6424) based on the national average monthly wage of RM3212 outlined in the National Salary and Wages Report 2022⁵⁷.

Instruments

Caregivers' burden was assessed using the 22-item Zarit Burden Interview. It is a self-reported questionnaire which measures the burden in several domains (burden in the relationship, emotional well-being, social and family life, finances, and loss of control over one's life). By using Likert scale from 0 to 4, the total score ranges from 0 to 88 which higher score represents higher perceived burden. Respondents can be classified into having caregiver burden (21–88) and no burden (≤ 20). It is then further classified into mild to moderate (21–40), moderate to severe (41–60) and severe (61–88)⁵⁸. In terms of reliability and validity, Boon et al. demonstrated good consistency (Cronbach's alpha of 0.93) and good test-retest reliability (alpha of 0.89)⁵⁹. As Malay language of ZBI was utilized in this study, it was previously validated with internal consistency (Cronbach's alpha of 0.88) and good test-retest reliability (alpha of 0.91)⁶⁰.

Statistical analysis

Descriptives were used to summarize both patients with AD and informal caregivers' demographics, ranges of ZBI scores and several different domains in caregiver's burden (ZBI). Continuous variables were expressed in mean and standard deviation (SD) while categorical variables were expressed as frequencies and percentage (%). Difference of sociodemographic of patients with AD-informal caregiver dyads between use of SpA was assessed using Pearson chi-square tests (categorical data) and ANOVA (continuous data). Caregiver burden scores between use of SpA were assessed using independent t-test (parametric) or Mann Whitney test (non-parametric) depending on the distribution of data. Moreover, potential association between caregiver's burden and demographics of both patients with AD and informal caregivers was tested using univariate linear regression. Categorical variables were converted to dummy variables before the analysis. The statistically significant value of the univariate linear regression was set at $p < 0.10$ ⁶¹. Only the significant independent variables were included into multivariable linear regression with ZBI scores as dependent variable which $p < 0.05$ shows statistical significance after controlling for the confounders. All analyses were conducted using the SPSS 27 software (IBM Corp. Released 2020. IBM SPSS Statistics for Windows, Version 27.0. Armonk, NY: IBM Corp).

Results

Socio-demographic characteristics of AD patients and caregivers

After approaching 161 potential respondents, 140 patient-caregiver dyads responded to the structured interview, achieving a response rate of 86.97%. After screening 140 patient profiles, 5 dyads were excluded as the patients with AD had not reached 65 years old during the first diagnosis. Among the included sample ($n = 135$), majority of them were community dwelling ($n = 113$, 83.7%) while the rest of them were supplemented with special accommodation care ($n = 22$, 16.3%).

Descriptives of the patient-caregiver dyads were presented in Table 1 in terms of demographics. The mean (SD) age of AD patients was 77.87 (6.7) years, with most being female ($n = 97$, 71.9%). 38 of them (28.1%) were

accompanied with other etiologies of AD dementia such as vascular and frontotemporal dementia. Based on the definition in DSM-V, there were 51, 55 and 29 patients grouped into mild, moderate and severe stage of AD respectively. Besides, BPSD were recorded in 43.7% of the patients ($n=59$). In terms of cognitive decline, the mean MMSE score of AD patients was 16.55 (5.74). In terms of functional needs, greater proportion of patients with SpA care required assistance in basic ADL ($n=16$, 72.73%) and instrumental ADL ($n=19$, 86.36%) respectively compared to community dwelling patients. However, most of the AD patients ($n=107$, 94.69%) reported more demand in supervision. With that, time spent on informal care was found increasing from basic ADL, instrumental ADL to supervision regardless of the use of SpA.

Most of the caregivers recruited were middle-aged with a mean age of 51.5 (13.6) years. Nearly two-thirds of them were female ($n=86$, 63.7%). Adult-child ($n=91$, 67.4%) occupied a major proportion in being a primary caregiver compared to spouse ($n=19$, 14.1%) and others ($n=25$, 18.5%). Most of them were staying with patients ($n=95$, 70.4%), employed ($n=91$, 67.4%) and married ($n=94$, 69.6%). The duration of caregiving provided was 2.87 (1.93) years with an average of 2.28 (1.38) caregivers involved in informal care. Regarding their monthly wage, over half ($n=75$, 55.6%) of them earned RM3212 and below, followed by those earned between RM3212 and RM6424 ($n=42$, 31.1%), and RM6424 and above ($n=18$, 13.3%). By comparing both groups, informal caregivers who utilized SpA were older (52.73 ± 14 years), accompanied with mixed etiology ($n=12$, 54.6%) and mostly male ($n=12$, 54.55%). There were more patients with moderate-severe AD ($n=18$, 81.8%) who utilized SpA than community dwelling patients ($n=66$, 58.4%). Measured by MMSE score, the cognitive function was recorded lower in those with SpA (15.05 ± 5.10) than in community dwelling patients with AD (16.76 ± 5.57). The number of caregivers involved with dementia care was higher in those with SpA (2.86 ± 2.1) than community dwelling patients (2.17 ± 1.2) while it was the opposite case in terms of duration of informal care provided where community dwelling dyads (2.92 ± 1.91) has longer duration than those with SpA (2.63 ± 2.12).

Caregivers' burden in Zarit burden interview

Most of the informal caregivers ($n=101$, 74.81%) reported caregiver burden based on ZBI scores compared to those who reported no burden ($n=34$, 25.19%). From Fig. 1, informal caregivers of community dwelling patients with AD (31.31 ± 16.08) recorded a greater burden score than those with special accommodation (29.36 ± 18.09). For community dwelling patients ($n=113$), the mean ZBI score increased significantly ($p<0.05$) from mild AD (28.04 ± 15.16) to severe AD (39.38 ± 15.64) while moderate AD recorded a ZBI score of 30.96 ± 16.25 . Looking into different ZBI domains in Table 2, burden in relationship (12.33 ± 4.16) and emotional well-being (11.81 ± 5.29) in severe AD was significantly higher ($p<0.05$) than in mild AD (8.81 ± 4.38 and 8.38 ± 4.82 , respectively). Although other aspects of ZBI were shown to be insignificant, an overall increasing trend was observed in all components and mean ZBI scores in caregivers of community dwelling patients across severities.

On the other side, the caregivers' burden of those who utilized SpA ($n=22$) increased inconsistently across disease severity in Table 3. The highest caregiver's burden was reported by those providing care for patients with moderate AD (37.7 ± 18.83), followed by severe AD (23.63 ± 10.12) and mild AD (20 ± 23.50). Similar trends were observed in different aspects of ZBI without exhibiting significance. While comparing caregiver burden scores between the use of SpA, statistical significance was detected in severe AD patients. For informal caregivers of severe patients who utilized SpA, their caregiver burden (ZBI = 23.63, $p<0.05$) was significantly lower ($p=0.024$) than community dwelling patients (ZBI = 39.38 ± 15.64).

Predictors of caregiver's burden among patients with AD in Malaysia

To identify potential predictors of caregivers' burden in Malaysia, the results of univariable and multivariable linear regression were shown in Table 4. Most of the variables were found non-significant except severe disease severity and spousal relationship with the patient. ($\beta=7.62$, $p=0.045$ and $\beta=11.71$, $p=0.026$). When they were inserted into multivariable linear regression, severe AD (standardised $\beta=0.187$, $p=0.047$ vs. mild AD) and spousal relationship (standardised $\beta=0.241$, $p=0.026$ vs. other relationships) were significantly associated with caregiver burden.

Discussion

This study evaluated the caregiver burden of informal caregivers who provided informal care to AD patients in both community and special accommodation care settings. Overall, the level of caregiver burden in this study was relatively higher than that in previous studies done in Asia^{10,11,21,23,36}. However, our finding was lower than those of informal caregivers from the USA and Spain which could be possibly explained by socio-cultural differences and caregiver characteristics^{12,62}. Compared with our neighbouring country, informal caregivers in Singapore recorded a lower burden score of 17^{23,36}. This was explained by the availability of extra hands to provide assistance in the society of Singapore³⁶. To compare our findings, a systematic review found that caregivers of people with dementia experienced moderate to high levels of burden in Malaysia⁴⁴. With the use of ZBI instrument, the burden was greater by the extent of 48.39% among caregivers residing in Sarawak state compared to our study⁴⁶. Health disparities portrayed by a lack of optimal resources and support for patients with AD could be a possible explanation^{44,63}.

In our analysis, severe AD was found to influence the caregiver burden significantly, which is consistent with previous studies^{7,14,21,34,64}. This could be explained by the deterioration of functional ability which was coherent with cognitive decline during disease progression^{6,14,22,53}. Increased time and effort were needed to perform ADL when AD deteriorates such as toileting, bathing and dressing^{7,29,30,45,65}. Such an increase in life dependence raised the amount of workload on informal caregivers^{64–66}. As their personal time was compressed, this may impose a negative influence on their work and family responsibilities^{7,14,28,33}. Exhaustion in physical and mental aspects was expected to bring detrimental influence on their perceived burden and QoL^{20,65}. This explained the significant increase in burden score among informal caregivers of community-dwelling patients

Use of special accommodation	Yes (n = 22)		No (n = 113)		Total (n = 135)		p-value
Patient							
Age in years (mean, SD)	80.00	5.35	77.46	6.85	77.87	6.68	0.103
Gender, n females (n, %)	15.00	68.18	82.00	72.57	97.00	71.85	0.676
Diagnosis, (n, %)							0.003***
AD	10.00	45.45	87.00	76.99	97.00	71.85	
Mixed Etiology	12.00	54.55	26.00	23.01	38.00	28.15	
Disease severity (n,%)							0.063
Mild	4.00	18.18	47.00	41.59	51.00	37.78	
Moderate	10.00	45.45	45.00	39.82	55.00	40.74	
Severe	8.00	36.36	21.00	18.58	29.00	21.48	
Presence of BPSD (n, %)	11.00	50.00	48.00	42.48	59.00	43.70	0.515
MMSE Score (mean, SD)	15.05	5.10	16.76	5.57	16.48	5.51	0.183
Functional Needs, n (%)							
BADL	16.00	72.73	74.00	65.49	90.00	66.67	0.51
IADL	19.00	86.36	92.00	81.42	111.00	82.22	0.579
SV	19.00	86.36	107.00	94.69	126.00	93.33	0.152
Mean caregiving time per month in hr, (SD)							
BADL	74.00	64.18	75.04	76.27	74.87	74.21	0.952
IADL	81.18	62.10	84.84	70.97	84.24	69.40	0.822
SV	160.45	95.37	154.69	113.92	155.63	110.80	0.824
Informal Caregiver							
Age in years, (mean, SD)	52.73	13.99	51.30	13.60	51.53	13.62	0.655
Female Gender (n, %)	10.00	45.45	76.00	67.26	86.00	63.70	0.052
Relationship with patient (n, %)							0.856
Spouse	3.00	13.64	16.00	14.16	19.00	14.07	
Adult Child	14.00	63.64	77.00	68.14	91.00	67.41	
Others	5.00	22.73	20.00	17.70	25.00	18.52	
Marital Status (n, %)							0.337
Married	12.00	54.55	82.00	72.57	94.00	69.63	
Single	9.00	40.91	26.00	23.01	35.00	25.93	
Divorced	0.00	0.00	1.00	0.88	1.00	0.74	
Widowed	1.00	4.55	4.00	3.54	5.00	3.70	
Cohabitation (n, %)	12.00	54.55	83.00	73.45	95.00	70.37	0.076
No. of caregivers (n, %)	2.86	2.10	2.17	1.17	2.28	1.38	0.030*
Employment status (n, %)	15.00	68.18	76.00	67.26	91.00	67.41	0.932
Presence of medical comorbidities (n, %)	10.00	45.45	47.00	41.59	57.00	42.22	0.737
Duration of informal care, yr (mean, SD)	2.63	2.12	2.92	1.91	2.87	1.94	0.518
Monthly Income level, RM (n,%)							
< 3212	13.00	59.09	62.00	54.87	75.00	55.56	0.811
3212–6423	7.00	31.82	35.00	30.97	42.00	31.11	
≥ 6424	2.00	9.09	16.00	14.16	18.00	13.33	
Caregiver's Burden, mean (SD)	31.31	16.08	29.36	18.09	30.99	15.37	
ZBI Range n (%)							0.294
No	6	27.27	28	24.78	34	25.19	
Mild-Moderate	11	50.00	53	46.90	64	47.41	
Moderate-Severe	2	9.09	26	23.01	28	20.74	
Severe	3	13.64	6	5.31	9	6.67	

Table 1. Sociodemographic of both patients with AD and informal caregivers in Malaysia. Remarks: P value for comparison of differences in means stratified by use of special accommodation using t test or differences in proportion using Pearson chi-square test. BADL indicates basic activities daily living; IADL, instrumental activities daily living; ZBI, Zarit Burden Interview; n, number of patients; SD, standard deviation. P value for comparison of differences in means across AD severity groups using ANOVA or differences in proportion using Pearson chi-square test; * denotes statistical significance of $p < 0.05$; ** denotes statistical significance of $p < 0.01$; *** denotes statistical significance of $p < 0.001$; ^R denotes reference.

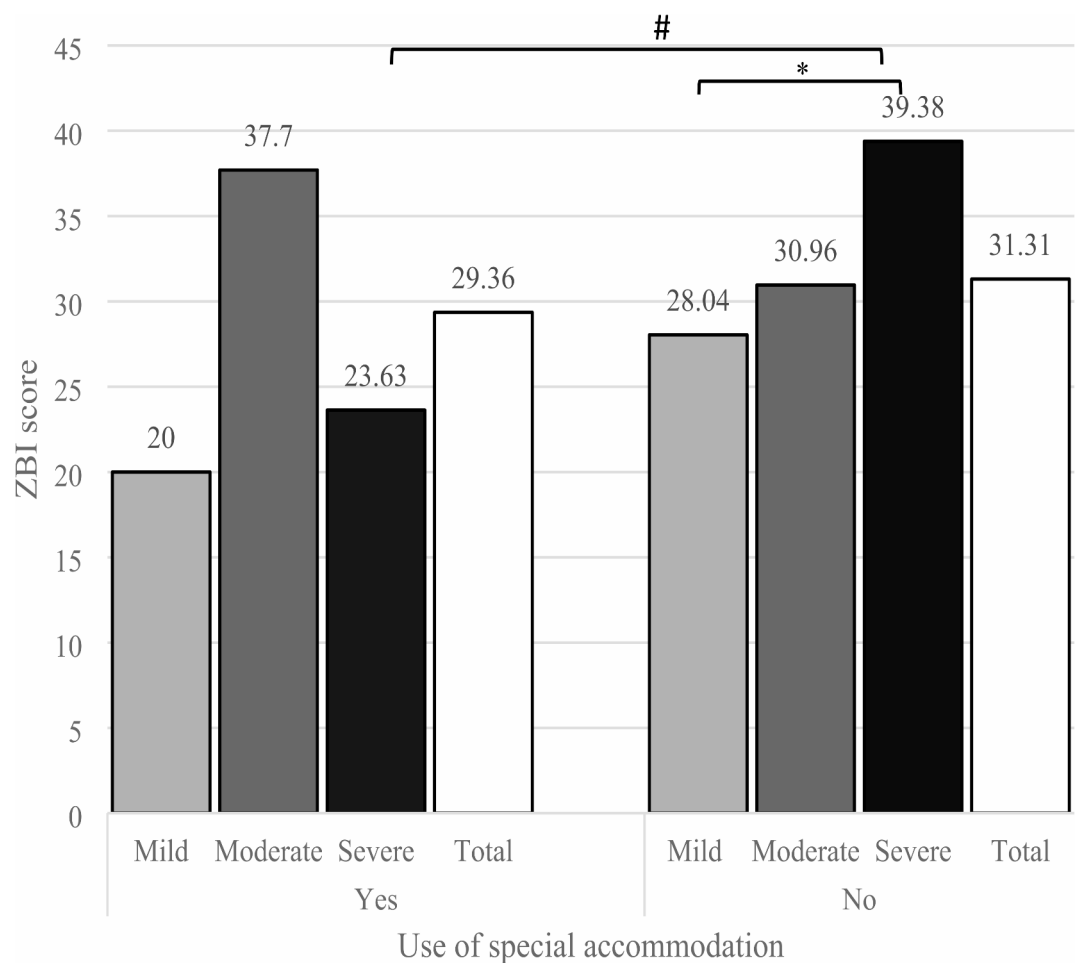


Fig. 1. Caregiver burden of informal caregivers of patients with different AD severities based on the use of special accommodation. Remarks: * denotes statistical significance ($P < 0.05$) in ANOVA; # denotes statistical significance ($P < 0.05$) in Mann-Whitney test due to the small sample size.

Care settings	Community-dwelling ($n = 113$)						
Disease Severity (n)	Mild ($n = 47$)		Moderate ($n = 45$)		Severe ($n = 21$)		
Domain of ZBI (score)	Mean	SD	Mean	SD	Mean	SD	p -value
Burden in the relationship (/6)	8.81 ^R	4.38	9.93	5.03	12.33**	4.16	0.02
Emotional Well Being (/7)	8.38 ^R	4.82	9.58	4.94	11.81*	5.29	0.03
Social and Family Life (/4)	4.60	3.18	4.82	3.61	6.57	4.64	0.11
Finances (/1)	1.11	1.15	1.42	1.20	1.76	1.22	0.10
Loss of control over one's life (/4)	5.15	3.60	5.20	3.21	6.90	2.90	0.10
Total ZBI score (/22)	28.04 ^R	15.16	30.96	16.25	39.38*	15.64	0.03

Table 2. ZBI score of informal caregivers in different domains stratified by disease severity among community dwelling AD patients. Remarks: n , number of patients; SD, standard deviation. P value for comparison of differences in means across AD severity groups using ANOVA or differences in proportion using Pearson chi-square test; * denotes statistical significance of $p < 0.05$; ** denotes statistical significance of $p < 0.01$; *** denotes statistical significance of $p < 0.001$; ^R denotes reference.

from mild to severe AD. When the caregiving threshold exceeds tolerable limits, time to institutionalization might be shortened in patients with deteriorating cognitive and functional ability³¹.

Besides, the spousal relationship was found to influence the caregiver burden significantly, which is consistent with prior studies^{5,62,65,66}. Traditionally, spousal caregivers were the ones who spent a vast amount of time co-residing with AD patients. As the closest person, spousal caregivers experienced a sense of obligation to provide

Care Settings	Special Accommodation (n = 22)						
Disease Severity (n)	Mild (n = 4)		Moderate (n = 10)		Severe (n = 8)		
Domain of ZBI (score)	Mean	SD	Mean	SD	Mean	SD	p-value
Burden in the relationship (/6)	7.25	7.37	11.90	4.31	7.13	3.68	0.09
Emotional Well Being (/7)	5.25	6.18	11.30	7.29	6.50	3.34	0.21
Social and Family Life (/4)	4.00	4.97	6.00	4.35	4.88	3.27	0.60
Finances (/1)	0.75	0.96	1.70	1.25	1.25	1.28	0.41
Loss of control over one's life (/4)	2.75	4.86	6.80	3.94	3.88	3.60	0.17
Total ZBI score (/22)	20.00	23.50	37.70	18.83	23.63	10.12	0.16

Table 3. ZBI score of informal caregivers in different domains stratified by disease severity among AD patients who utilized special accommodation. Remarks: n, number of patients; SD, standard deviation. *P* value for comparison of differences in means across AD severity groups using Kruskal Wallis test due to small sample size; * denotes statistical significance of $p < 0.05$; ** denotes statistical significance of $p < 0.01$; *** denotes statistical significance of $p < 0.001$; ^R denotes reference.

care for their partners, especially females^{6,36,45,67}. In addition, increasing the age of the spouse may increase difficulty when assisting in daily caregiving tasks particularly mobility tasks that require physical strength^{5,65}. Not only that, rising concerns might occur in socioeconomic, healthcare and emotional needs among ageing caregivers^{23,28,68}. For instance, the chances of having depression were 2.51 times higher in spousal caregivers of AD in a meta-analysis¹⁹. With that, the government could provide essential support to family caregivers particularly spouses depending on various challenges at different disease stages^{5,67,69}. For instance, measures such as home visit for those staying far from healthcare facilities and caregiver emotional support groups could lessen caregivers' hassle in making extra arrangements for medical consultations^{46,70}. Not only it could provide positive feedback, such measures could also benefit caregivers to recover from negative emotions resulted from long-term burnout^{7,65,71}.

Nevertheless, no significant difference in caregiver burden was detected between adult-child and spouse in this study, which is consistent with some previous studies^{33,72}. However, Conde-Sala et al. reported that adult-child experienced a greater burden than spousal caregivers especially those who co-resided with AD patients⁶⁶. Such a trend was also observed in several studies conducted in Western countries^{14,73}. On the other side, mixed findings were revealed by some other studies that spousal caregivers reported greater subjective burden, particularly in the later stages of dementia^{35,37,65,69}. Such a scenario could be due to their duty as a sole caregiver to undertake both informal caregiving and household tasks³⁵. Surprisingly, the increase in burden among female caregivers was not significant in this study which was inconsistent with previous studies^{15,28,35,65}. Findings of higher strain among female caregivers compared to men may be due to cultural expectations of gender in family responsibility^{35,47,65}.

Interestingly, BPSD were found not significantly impact on caregiver burden in this study, which contrasts with previous studies^{10,11,15,28}. Among BPSD, irritability, agitation, sleep disturbances, anxiety, apathy, and delusion were found to impact greatly on caregivers' burden^{8,11,74,75}. This could be explained by the variations in cultural perceptions and practices between different regions^{33,37,76}. Cultural conceptualizations in Asian caregivers help them to accept and endure the hardship of illness as part of filial piety unlike in Western practice. With that, Asian caregivers seldom seek help or express their needs compared to Western caregivers, which partially explains this finding⁶⁷. Nevertheless, a higher risk of institutionalization was observed in AD patients with BPSD besides the length of hospital stays and use of emergency rooms^{23,31}. Additionally, it influences the mental aspects of caregivers with a higher prevalence of depression and anxiety reported among caregivers of AD patients due to emotional exhaustion^{19–21,62}. Our study finding may be due to subjective caregivers' responses and the absence of clinical instruments to evaluate the degree of BPSD in this study. Future studies could incorporate evaluation tools such as the Neuropsychiatry Index (NPI) to evaluate the presence of BPSD and its influence on caregivers' burden in different domains among AD patients in Malaysia.

The analysis revealed no statistically significant associations between caregiver burden and sociodemographic variables, including patient age^{15,34,36}, caregiver age, cohabitation status^{10,21,23,66}, number of caregivers^{21,65}, marital status³⁶, or household income⁶⁸. Notably, a prior local investigation further corroborated this finding, reporting no statistically meaningful link between caregiver sociodemographic and burden levels, though constrained by limited sample size⁴⁸. The overrepresentation of female patients in the caregiver cohort, likely reflective of gender-based longevity trends, did not yield differential burden outcomes, suggesting that sex-based disparities in care needs may not directly translate to caregiver strain^{48,67}.

Contrary to expectations, caregiving-related variables, including functional needs and time allocated to ADL also failed to predict burden levels. For instance, Park et al. (2015) identified IADL demands, particularly housekeeping tasks, as a key contributor to burden in Korean populations⁵. Similarly, increased caregiving duration has been associated with elevated burden perceptions⁶⁵, though this relationship was not observed in the present analysis. This contrasts with previous finding that identified IADL tasks (e.g., housekeeping) as a critical burden driver in Korean caregivers⁵. Similarly, increased caregiving duration, previously linked to heightened burden perceptions did not demonstrate predictive utility here⁶⁵. These discrepancies may reflect cultural or methodological variations, such as differences in task delegation norms or measurement tools.

Independent variables	Univariable analysis			95% CI		Multivariable Analysis				95% CI	
	β	p value	SE	Lower	Upper	β	Std β	p value	SE	Lower	Upper
Patient variable											
Patient Age	0.072	0.736	0.213	-0.349	0.492						
Female Gender	-2.977	0.344	3.134	-9.145	3.222						
Diagnosis (Ref: AD)											
Mixed Etiology	1.805	0.566	3.141	-4.407	8.017						
Disease variable											
Disease Severity, n (%)											
Mild	Ref					Ref					
Moderate	4.77	0.133	3.152	-1.465	11.005	5.489	0.165	0.08	3.116	-0.675	11.653
Severe	7.623	0.045	3.771	0.164	15.082	7.428	0.187	0.047	3.71	0.088	14.768
Presence of BPSD	3.927	0.168	2.831	-1.672	9.526						
MMSE Score	-0.238	0.356	-0.08	-0.745	0.27						
Functional Needs, n (%)											
BADL	3.819	0.288	2.987	-2.719	9.097						
IADL	5.768	0.118	3.665	-1.481	13.017						
SV	-1.675	0.768	5.667	-12.884	9.535						
Mean caregiving time per month, (SD)											
BADL	0.013	0.502	0.019	-0.025	0.051						
IADL	0.023	0.253	0.02	-0.017	0.064						
SV	-0.009	0.466	0.013	-0.035	0.016						
Informal Caregivers											
Caregiver Age	0.115	0.269	0.104	-0.09	0.32						
Female Gender	4.377	0.136	2.916	-1.391	10.146						
Relationship with patient											
Spouse	11.706	0.026	4.926	1.331	20.82	10.969	0.241	0.026	4.862	1.351	20.586
Adult Child	4.738	0.197	3.655	-2.492	11.968	5.241	0.163	0.149	3.615	-1.909	12.392
Others	Ref					Ref					
Cohabitation	0.025	0.994	3.097	-6.101	6.151						
Marital Status (Ref: Single/Divorced/Widowed)											
Married	-3.478	0.258	3.06	-9.532	2.575						
No. of caregivers	-1.209	0.239	1.023	-3.233	0.814						
Employment	-0.483	0.873	3.017	-6.45	5.484						
Presence of medical comorbidities	1.349	0.638	2.861	-4.309	7.007						
Use of Special Accommodation	-1.946	0.612	3.825	-9.512	5.62						
Mean duration of informal care in years	-0.761	0.299	0.729	-2.203	0.681						
Monthly Income Level											
< 3212	Ref										
3212–6423	-1.089	0.731	3.154	-7.327	5.15						
≥ 6424	-6.216	0.15	4.295	-14.711	2.28						

Table 4. Multivariate linear regression of caregiver's burden (Zarit burden interview score) among informal caregivers and AD patients in Malaysia. Remarks: In multivariable analysis, the model $R^2 = 0.069$. β unstandardised beta; std β standardised beta; AD: Alzheimer's disease; PWAD: Patient with Alzheimer's disease; CG: Caregiver; BADL: Basic Activity of Daily Living; IADL: Instrumental Activity of Daily Living; SV: Supervision; BPSD: Behavioural and Psychological Symptoms of Dementia; MMSE: Mini- Mental State Examination.

Regarding the use of SpA care, reduction of caregiver burden was found among informal caregivers particularly those who cared for patients with severe AD in this study. This finding is consistent with previous studies as professional formal care services from SpA improved caregiving experiences among informal caregivers^{34,77}. With the aid of trained AD care, the functional demands of severe AD patients could be accommodated by professional healthcare workers in SpA by sharing the time and intensity of daily caregiving tasks^{5,15,17}. With that, informal caregivers were able to spend more time on personal development and work performance^{34,64,77}. In addition, informal caregivers could relieve mental stress due to the emotional needs of patients with AD via formal assistance from SpA^{40,69}. Due to the need for long-term supervision, SpA stood up as a better alternative in dealing with BPSD such as aggressiveness and delusion^{5,15}. With that, caregivers' resilience could be improved by providing them time off in sharing long-term caregiving tasks^{69,71}.

Results from prior longitudinal studies suggest SpA use as an alternative to reduce QoL loss in informal caregivers^{15,39,78}. Due to the phenomenon of population ageing, there is an increasing demand for AD care services via the public healthcare system in Malaysia^{42–44}. Considering the increasing prevalence of dementia, the establishment of special accommodation care could be considered by healthcare stakeholders to target different types of caregiver burden among informal carers^{33,47}. With good social support such as special accommodation care, reduced caregiver burden could be anticipated especially in severe stages of AD as observed in previous studies^{46,70,77}.

The strength of this study was the use of ZBI as a comprehensive measuring tool in determining caregiver burden. Such results enabled cross-comparison with burden estimates from different countries. Next, this study presented the latest estimates of caregiver burden among informal caregivers of AD patients who resided in both community and SpA care settings. Such estimates are very important from the societal perspective as overburdened caregivers may struggle to maintain a high standard of care towards care recipients⁷⁷. With such real-world findings, informed decision-making could be done by healthcare policymakers in addressing the needs of caregiver support under the framework of the Malaysia dementia action plan 2023–2050⁷⁹.

However, there were some limitations to be taken note. Firstly, the study population was not representative of the whole population of AD patients in Malaysia, which limits the generalizability of the findings. In addition to that, the results regarding patients with SpA care need to be interpreted with caution due to the small sample size. Next, the use of special accommodation was recorded based on presenteeism where the details were not sought due to missing data. Such limited evidence renders difficult for policymakers to identify the actual effect of SpA in alleviating caregivers' burden as the type, feature and duration of SpA use were not consistent across the study population. Future studies could incorporate more precision during data collection of SpA use such as SpA type and duration of use. Other than that, caregivers' responses might be subject to recall bias when obtaining time spent on informal care due to memory recall of 3 months. In order to evaluate the effect of long-term caregiving towards caregivers' burden, a longitudinal study design could be considered in future assessments. Besides, the study was unable to test all potential factors such as the education level of patient due to the inability to gain information from the interviews with caregivers. It is suggested to incorporate more relevant factors into future analysis.

Conclusion

Informal caregivers significantly contribute to the care of patients with AD who are highly dependent. However, their physical and social needs must not be overlooked. This study found that informal caregivers of AD patients residing in the community experienced a higher level of burden compared to those who utilized special accommodation care, particularly in cases of severe AD. Spousal caregivers, often the closest to AD patients, also reported a greater burden when providing informal care. It is crucial for policymakers to address the needs of caregivers to accommodate their physical and mental stress. Social support is important to mitigate caregivers' workload with multiple coping measures. Special accommodation care may serve as a viable option for severe AD patients, potentially reducing caregiver stress and improving their QoL.

Data availability

The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

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Author contributions

SCO and LXT were involved in conception and design of the study. LXT performed interpretation of data and statistical analysis. SCO and TP conducted critical revision of the manuscript for important intellectual content, obtaining funding and supervision. All authors contributed to the manuscript revision, read, and approved the submitted version.

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Declarations

Competing interests

The authors declare no competing interests.

Ethical issues

The study obtained ethical approval from the Medical Research and Ethics Committee (NMRR-21-02014-VCP(IIR)).

Disclaimers

The views expressed in this publication are those of the author(s) and not necessarily those of the Ministry of Science, Technology, and Innovation (MOSTI), Malaysia.

Additional information

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