Geriatric Nursing 40 (2019) 380–385

Contents lists available at ScienceDirect

Geriatric Nursing

journal homepage: www.gnjournal.com

Feature Article

Factors associated with high strain in caregivers of Alzheimer's disease (AD) in Malaysia

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ARTICLE INFO

Article history:
Received 18 July 2018
Received in revised form 24 December 2018
Accepted 28 December 2018
Available online 11 February 2019

Keywords:
Alzheimer's disease
Caregiver strain
Resilience

ABSTRACT

A cross-sectional study design involving a total of 230 participants, recruited through Alzheimer's Disease Foundation Malaysia (ADFM), was adopted to access and correlate caregiver strain index (CSI) and resilience (RES) levels of the AD caregivers with various patients' and caregivers' factors. Findings revealed that 77.7% of caregivers had a high level of stress, and there was a significant negative correlation between RES and CSI ($P < 0.001$). Care recipients' physical function was negatively associated with CSI level. Caregivers' gender and employment status were not directly associated with CSI but were significantly associated with caregivers' RES level. Among the mediator variables, years of care was related to increase CSI and adult-children of AD patients experienced a higher level of caregiver strain compared to the other caregiver groups ($P = 0.025$). Thus, interventions to improve the family caregivers' RES level, and support for AD patients will be helpful in lowering the strains of AD caregivers.

Introduction

The aging population worldwide has increased the number of patients with Dementia.[2] It is estimated that there are more than 35 million people worldwide living with Alzheimer's disease (AD) or a related form of dementia.[28] The age distribution of Malaysia's population had changed dramatically over the past years where the percentage of elderly population (age 60 years or over) had increased from 5.5 to 7.9% from 1970 to 2010 while the population aged less than 20 years old had decreased by 18.3% in the same period. The elderly population is projected to reach 16.3% of the total population by the year 2040.[23] This indicates that AD is going to be a healthcare burden in near future. Therefore, appropriate measures to improve AD-related healthcare in Malaysia are crucial.

The role of caregivers is a central and integral part of the management of AD patients.[29] Although caregiving may bring personal gains and satisfaction, caregivers most often provide these services to the society and their family members at substantial personal cost. Many AD caregiving involves both negative and positive aspects. A cross-sectional study involving primary caregivers of Dementia patients from five major government hospitals in Sarawak, Malaysia reported that Dementia caregivers in the local settings experienced poor physical and mental health. Its associated factors include race, behavior problems with patients, employment status and type of Dementia.[22] Study conducted by Choo et al.,[6] showed that caregiver burden was associated with both ethnicity and informal support. According to Zarit and Zarit,[30] the extent of burden reported by primary caregivers with Dementia was associated with the availability of social support, and was not related to the behavior problems caused by the illness. Caregivers who have a greater emotional and social support usually reported a higher level of life satisfaction.

While majority of existing research tend to consider caregiving sample as relatively homogeneous, where various socio-demographic characteristics, care demands, and stressors are empirically controlled, Dias et al.[10] suggested that creating typologies of caregivers based on constructs such as resilience may better inform the practitioners as to the type and timing of certain interventions. Resilience is the ability of caregivers to preserve in at-home caregiving roles while remaining stable or decreasing on key caregiving indicators such as burden and depressive symptomatology. Resilience appears to account for diverse caregiving outcomes over time. Resilience is considered as successful adaptation and competence that results in effective functioning in the face of stressful situations.[12] Therefore, people with high resilience level are able to recover from negative events.[8] Adopting the Transactional Model of Stress and Coping,[1] resilience has been identified as a concept that can mediate between the individual and the environment through appraisal of the external stressors and by coping with stressful events.

Therefore, from the clinical perspective, caregiver's resilience level may impact the appraisal of the caregiving burden and the

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https://doi.org/10.1016/j.gerinurse.2018.12.009
0197-4572/$ – see front matter

development of positive or negative coping strategies. If resilience is indeed identified as a moderator of burden in AD caregivers, it follows that resilience enhancing support and education programs could be developed to strengthen a caregiver's ability to care for their loved ones.

The aims of this study were: (1) to explore the caregiver strains and resilience level of caregivers of patients with AD in Malaysia, (2) to determine the factors associated with caregiver strains in caregivers of AD patients, and (3) to determine the effect of resilience on the relationship between caregiver strains and caregivers or patient's factors. In this study, the strain levels of the AD caregivers were assessed and correlated with patients' and caregiver's factors i.e. primary stressors variables, primary appraisal variables, mediator variables, and resilience level. The conceptual model guiding the current study (Fig. 1.) is based on the model proposed by Yu et al.[29] and Gaugler et al.[12] At the heart of the model is the construct of resilience, which is defined by high or low burden in the presence of various levels of care demands. This caregiver assessment could be instrumental in identifying the appropriate system changes that can improve community-based health care delivery.

Methods

Study participants

A cross-sectional study design on AD caregivers was conducted. Participants were caregivers who are taking care of AD patients, recruited through Alzheimer's Disease Foundation Malaysia (ADFM). In this study, a caregiver is defined as a person who provides care for an elderly relative with AD who needs assistance in performing daily activities. The caregiver selection criteria includes the following: (1) the care recipients are outpatients diagnosed with AD by a physician; (2) is the person who maintains frequent contact with the patient; (3) is the person who knows the patient well and has an idea of how the patient typically behaves; (4) is the person who is able to understand one of these languages - Bahasa Malaysia, English or Mandarin. The caregivers were excluded from the study if they had malignant or severe organic or psychiatric diseases that made it impossible to complete the study questionnaires; did not provide inform consent; caring for more than one chronically ill person in the family. This study was approved by International Medical University Joint-Committee on Research & Ethics (4.4/JCM-111/2016). The questionnaires were given out to the participants after each training workshop by ADFM in different states throughout Malaysia. Informed consent was obtained from caregivers. Data collection started in January 2017. During the study period, 230 caregivers of AD patients were recruited. Of these, 207 (90%) caregivers fulfilled the criteria and completed the questionnaires.

Measures

Caregivers were asked to provide data information on sociodemographic characteristics, socioeconomic, and caregiving hours including caregiver relationship to patient, and support/living situation through the study's questionnaire. The questionnaires which were originally in English were translated into Bahasa Malaysia and Mandarin via the back-translation technique. Caregivers were also asked to complete three instruments to assess their strain of caregiving, resilience level and the care recipient's ability to perform activities of daily living independently.

Brief resilience scale (BRS)

The Brief Resilience Scale (BRS) is a six-item questionnaire assessing the ability to bounce back or recover from stress. BRS consist of a range of resilience-related constructs, personal characteristic, coping styles, social relationships, and health-related outcomes. Three questions are positively worded while the other three are negatively worded. The BRS is scored by reserve coding the questions that are negatively worded and finding the mean of the six items. The higher the score, the higher the resilience level.[25,19]

Katz index of independence in activities of daily living (Katz ADL)

The Katz Index of Independence in Activities of Daily Living (Katz ADL) assesses functional status as a measurement of the care recipient's ability to perform activities of daily living independently. The Katz Index ranks adequacy of performance in the six functions of bathing, dressing, toileting, transferring, continence, and feeding. Care recipients are scored yes/no from independence in each of the six functions. A score of six indicates full function, four indicates moderate impairment, and two or less indicates severe functional impairment.[17]

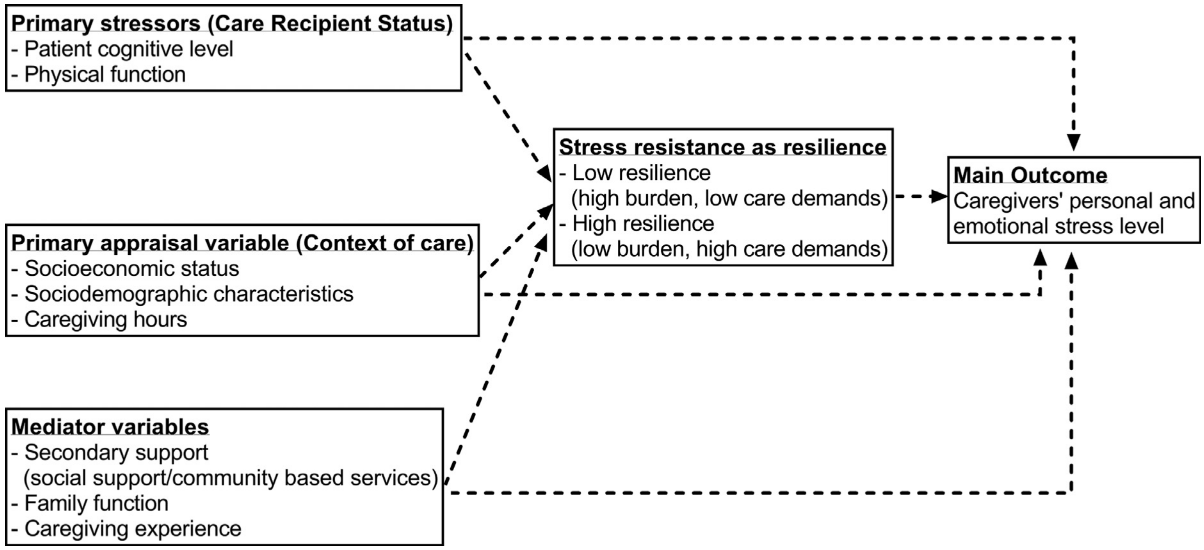

Fig. 1. Conceptual model. Strain levels of the AD caregivers and its correlations with patient and caregiver factors i.e. primary stressors variables, primary appraisal variables, mediator variables, and resilience level.

Modified caregiver strain index (CSI)

The Modified Caregiver Strain Index (CSI), is a 13-item questionnaire measuring the caregiver strain related to care provision. There is at least one item for each of the following major domains: employment, financial, physical, social and time. Scoring is two points for each ‘yes’, and one point for each ‘sometimes’ response. The higher the score, the higher the level of caregiver strain.[27]

Statistical analysis

For preliminary analysis of the three variables (i.e. primary appraisal variable, primary stressors and mediator variable of caregivers), we used descriptive statistics such as means and standard deviation (SD) for qualitative data, and frequencies and percentages for categorical variables. The main outcome in this study was caregiver strain index (CSI). Care recipients’ independence in daily living was treated as primary stressors; the primary appraisal variable included sociodemographic characteristics and caregiving hours. Mediator variables included years of care and secondary support (Fig. 1). The difference of CSI and caregiver resilience level (RES) in three variables (i.e. primary appraisal variable, primary stressors and mediator variable of caregivers) was examined using *t*-test or analysis of variance (ANOVA). Pearson correlation analysis was performed to identify correlations between caregivers’ age and years of care with CSI and RES. Path analysis was used to build the interrelationships among CSI and caregiver or care recipients’ factors. As the care recipients’ physical status, kinship, caregivers’ employment status, gender, and education are categorical variables, they were included in the regression analysis as dummy variables. Multiple linear regression was also performed to evaluate the effect of resilience on CSI. Data were analyzed using Statistical Analysis Software (version 9.3 SAS Institute Inc., Cary, NC) and SPSS software (version 25.0). The significant value was set at $P \le 0.05$.

Results

Preliminary analyses

Table 1−3 shows the three variables (i.e. primary appraisal variables, primary stressors and mediator variables of caregivers), and the comparison of caregivers’ resilience and caregiver strain index with these three variables: primary appraisal variables (Table 1), primary stressors (Table 2) and mediator variables (Table 3).

The mean age of the caregivers was 50.4 years (SD = 14.5). More than half of them were females (79.7%) and married (59.9%). In term of ethnicity, Chinese was the majority (57.2%), followed by Malay (13.5%), Indian (8.7%) and 10.6% were Bidayuh, Kadazan and others. Meanwhile the education level of caregivers was 20.3% with informal or lower education and 77.3% had college or university education. Most of the caregivers (59.9%) were employed either full time or part time, and 39.6% of caregivers were unemployed, homemaker or retiree. The relationship between caregiver and patient was as follows: 16.4% were spouse, 61.4% children, and 17.4% were identified as “others.” Daily caregiving duties lasted for more than eight hours in 46.4% of the caregivers and 35.3% of caregivers were involved in less than eight hours duty. The mean number of years of care provided by each caregiver was four years (±4.1), with a range of 2 months−25 years.

The caregiver strain index (CSI) was determined as 12.0 ± 5.8 (mean ± SD) and caregiver resilience level as 19.2 ± 3.3 (mean ± SD).

Table 1
Comparison of Caregiver Strain Index (CSI) and Resilience Scale (RES) of caregivers with primary appraisal variables.

Primary appraisal variables (context of care)	*N* (%)	Caregiver Strain Index (CSI)		Resilience Scale (RES)	
		Mean (±SD)	*P* value	Mean (±SD)	*P* value
Gender					
Male	42 (20.3)	11.6 (±5.8)	0.592	20.3 (±3.8)	0.033[**]
Female	165 (79.7)	12.1 (±5.8)		18.9 (±3.2)	
Ethnicity					
Malay	28 (13.5)	12.6 (±5.4)	0.689	19.4 (±3.1)	0.442
Chinese	139 (67.1)	12.2 (±5.9)		19.3 (±3.4)	
Indian	18 (8.7)	11.6 (±6.5)		18.1 (±4.3)	
Others	22 (10.6)	10.7 (±4.9)		18.6 (±1.5)	
Marital status					
Spinsterhood	75 (36.2)	12.8 (±6.2)	0.421	19.1 (±3.2)	0.860
Married	124 (59.9)	11.6 (±5.5)		19.2 (±3.5)	
Others	7 (3.4)	11.6 (±5.2)		18.5 (±1.9)	
Do not know	1 (0.5)	NA		NA	
Education level					
Informal/lower education	42 (20.3)	10.4 (±5.9)	0.047[**]	18.7 (±3.0)	0.333
College/University	160 (77.3)	12.5 (±5.7)		19.3 (±3.4)	
Do not know	5 (2.4)	NA		NA	
Employment status					
Employed (full time/part time)	124 (59.9)	12.5 (±5.8)	0.220	18.8 (±3.5)	0.046[**]
Unemployed/homemaker/retiree	82 (39.6)	11.4 (±5.8)		19.7 (±2.9)	
Do not know	1 (0.5)	NA		NA	
Kinship					
Spouse	34 (16.4)	10.0 (±5.6)	0.025[**]	19.2 (±3.6)	0.804
Offspring	127 (61.4)	12.8 (±5.8)		19.3 (±3.5)	
Others	36 (17.4)	11.2 (±4.9)		18.9 (±2.5)	
Do not know	10 (4.8)	NA		NA	
Hours of care					
≤8 h	73 (35.3)	12.5 (±6.0)	0.594	19.1 (±4.2)	0.755
>8 h	96 (46.4)	12.0 (±5.6)		19.3 (±3.0)	
Do not know	38 (18.4)	NA		NA	

The higher the Caregiver Strain Index (CSI), the higher level of caregiver strain (0−26).
The higher the Resilience Scale (RES), the higher level of caregiver resilience (0−30).
[**] Significant level at $P \le 0.05$; Abbreviation: NA, not applicable.

Table 2
Comparison of Caregiver Strain Index (CSI) and Resilience Scale (RES) of caregivers with primary stressors (care recipient status).

Primary stressors (care recipient status)	*N* (%)	Caregiver Strain Index (CSI)		Resilience Scale (RES)	
		Mean (±SD)	*P* value	Mean (±SD)	*P* value
Kartz index of independence in activities of daily living					
Severe functional impairment	30 (15.8)	14.1 (±6.4)	0.009**	19.3 (±2.4)	0.258
Moderate functional impairment	62 (32.6)	13.1 (±5.0)		18.5 (±3.6)	
Full function	79 (41.6)	10.9 (±5.6)		19.3 (±3.3)	
Do not know	19 (10.0)	NA		NA	

The higher the Caregiver Strain Index (CSI), the higher level of caregiver strain (0–26).
The higher the Resilience Scale (RES), the higher level of caregiver resilience (0–30).
** Significant level at $P \leq 0.05$; Abbreviation: NA, not applicable.

Notably, 161 caregivers in this study reported a score of seven or more on the CSI, which is the cutoff score used by the scale's originator.[11] This indicated that 77.7% of caregivers had a high level of stress. On the other hand, the caregiver resilience level was above medium level (on a scale of 0–30).

When the CSI were examined according to the primary appraisal variables, it was found that there was a significant difference based on the caregivers' education ($P = 0.047$) and caregivers' relationship with care recipients ($P = 0.025$) (Table 1). As for primary stressors and mediator variables, the CSI differed in terms of the care recipient independence in activities of daily living ($P = 0.009$) (Table 2), and the years of care ($P = 0.020$) (Table 3). In regard to caregivers' resilience level, caregivers' gender ($P = 0.033$) and caregivers' employment status ($P = 0.046$) were the only variables showing statistical significance associated with it (Table 1).

Correlation analyses

Correlation analyses suggested that caregivers' age (primary appraisal variable) was not associated with CSI ($r = -0.12$, $P = 0.10$) and resilience ($r = 0.08$, $P = 0.29$). Years of care (mediator variable) was correlated with CSI ($r = 0.173$, $P = 0.018$) but not resilience ($r = -0.085$, $P = 0.253$). However, a significant negative correlation between resilience and CSI was found ($r = -0.30$, $P < 0.01$).

Caregiver strain index (CSI) and its relationship to primary appraisal variables, primary stressors and mediator variables of caregivers

The final path model is shown in Fig. 2. For primary stressor, the care recipients' physical function had significant direct effects on CSI when controlling for all other variables in the model. Care recipients' physical function was negatively associated with CSI ($r = -0.23$, $P < 0.01$), with a lower physical function in care recipients leading to a higher CSI. Regarding the primary appraisal variables, kinship was positively related to CSI ($r = 0.18$, $P < 0.05$). The other two primary appraisal variables, caregivers gender and employment status were not directly associated with CSI but were significantly associated with caregivers' RES level. Caregivers' education level was not associated with both CSI and RES. Among the mediator variables, years of care ($r = 0.17$, $P < 0.05$) was related to increase CSI, with longer years of caring leading directly to higher CSI (Fig. 2).

Multiple regression analyses

Regression analysis was performed to determine the contribution of various variables related to caregiver strain based on CSI. A significant correlation was observed between caregiver strain and caregivers' education level, caregivers' relationship with care recipients, care recipients' physical function and years of care. These variables

Table 3
Comparison of Caregiver Strain Index (CSI) and Resilience Scale (RES) of caregivers with mediator variables.

Mediator variables	*N* (%)	Caregiver Strain Index (CSI)		Resilience Scale (RES)	
		Mean (±SD)	*P* value	Mean (±SD)	*P* value
Living in same household					
Yes	135 (65.2)	11.7 (±5.7)	0.225	19.1 (±3.5)	0.852
No	69 (33.3)	12.7 (±5.9)		19.2 (±3.0)	
Do not know	3 (1.4)	NA		NA	
Years of care					
≤5 years		11.6 (±5.4)	0.020**	19.4 (±3.6)	0.419
6–10 years		13.6 (±6.6)		18.8 (±2.4)	
>10 years		16.5 (±5.7)		18.2 (±2.1)	
Helps from family members					
Yes	163 (78.7)	12.3 (±5.8)	0.271	19.3 (±3.3)	0.170
No	44 (21.3)	11.1 (±5.8)		18.5 (±3.3)	
Emotion support					
Yes	135 (65.2)	11.7 (±5.7)	0.404	19.2 (±3.4)	0.943
No	65 (31.4)	12.5 (±5.8)		19.1 (±3.2)	
Do not know	7 (3.4)	NA		NA	
Hire help					
Yes	98 (47.3)	12.4 (±5.9)	0.396	19.1 (±3.3)	0.931
No	106 (51.2)	11.7 (±5.6)		19.2 (±3.4)	
Do not know	3 (1.4)	NA		NA	

The higher the Caregiver Strain Index (CSI), the higher level of caregiver strain (0–26).
The higher the Resilience Scale (RES), the higher level of caregiver resilience (0–30).
** Significant level at $P \leq 0.05$; Abbreviation: NA, not applicable.

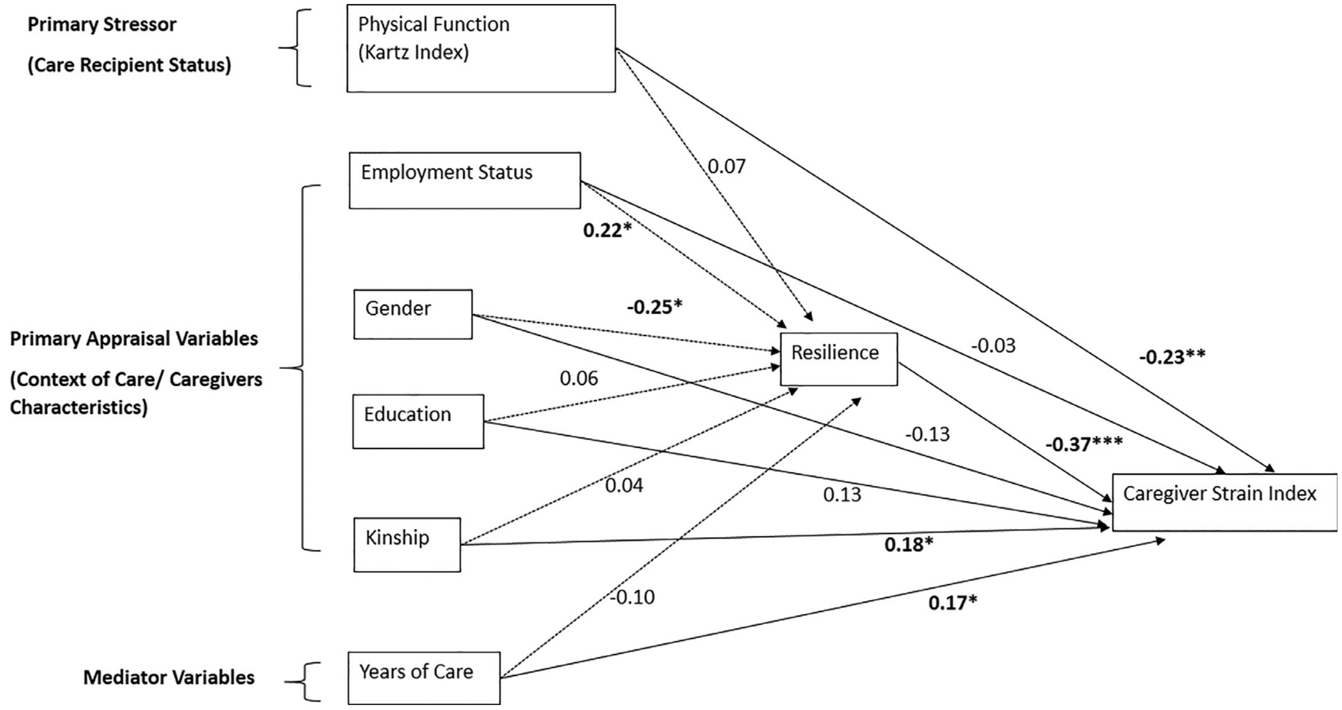

Fig. 2. Path analysis to identify factors influencing resilience and caregiver strain index in AD caregivers. *Significant effects shown as standardized coefficients (betas) are noted with the symbol (*$P < 0.05$, **$P < 0.01$, ***$P < 0.001$).

were included in the regression model. Results showed that the care recipient independence in daily activities is a significant predictor for CSI. As the level of the care recipient independence in daily activities increases, the CSI decreases. In the second model, caregiver resilience was entered into the regression equation to determine the effect of RES on CSI. It was found that there was a significant effect of RES ($\beta = -0.34$), $P < 0.001$) on CSI, and this variable explain 20% of the variance in CSI (Table 4).

Discussion

This study attempted to assess the strain and resilience levels of the AD caregivers and their correlation with patients and caregivers' factors, as well as the association between the caregivers' resilience and strain levels.

Results showed that most of the caregivers had a high level of stress. As for primary stressor and mediator variables, the CSI differed in terms of the care recipient independence in activities of daily living. It means that a higher strain score among the caregivers is significantly related to the severe functional impairment among the AD patients. Several studies have confirmed that the level of cognitive and behavioral impairment in AD patients is related to increased caregiver burden.[9,16,26] Furthermore, a research by Mohamed et al.[21] showed that severe psychiatric and behavioral problems and decreased AD patients' quality of life are significantly associated with higher levels of depression among caregivers. In addition, the years of care provided by caregivers is significantly associated with the strain score; as the number of caregiving years increases, the caregivers experience a higher level of strains. In a longitudinal study, Conde-Sala et al.[7] reported that the AD caregiver burden increases over the years of caregiving mostly due to the increased damage to the patients' physical and mental health through the process of disease progression.

Table 4
Regression analysis: Predictors of caregiver strain index (CSI) of caregivers.

Variables	Model 1	Model 2
Primary appraisal variable		
Caregiver's characteristic		
Education level	0.131	0.140
Kinship (1 = offspring, 0 = others)	0.137	0.141
Primary stressors		
Independence in activities of daily living (1 = full function, 0 = moderate/severe functional impairment)	−0.172*	−0.136
Mediator variable		
Years of care	0.106	0.091
Resilience		−0.338***
Model F	3.862**	7.551***
R^2	0.091	0.200
ΔR^2	0.067	0.174

* $P < 0.05$.
** $P < 0.01$.
*** $P < 0.001$.

Moreover, significant negative correlation was found between RES and CSI, and there was a significant effect of resilience on caregiver strain. Overall, caregivers with higher resilience score experienced significantly lower level of caregiver strain. A similar research indicated that as resilience in AD caregivers increases, their caregiver burden decreases.[14] Research by Dias et al.[10] showed that higher levels of caregiver resilience were associated with lower depression rates and greater physical health. The study indicated that main psychological factors associated with higher resilience were lower burden and stress, and perceived control. Hence, social support was a moderating factor of resilience,[10] and different types of social and psychological support were found to be helpful in relieving the physical and mental overload caused by stress.[3,10] These findings suggested that supportive interventions are needed in order to increase resilience in AD caregivers.

Hence, a significant correlation was observed between caregivers' relationship with care recipients. The majority of caregivers were adult-children of AD patients, and they reported a significantly higher strain score compared to other caregiver groups. This is consistent with an earlier study demonstrating that adult-child caregivers experience a higher level of burden compared to spousal caregivers.[24] Adult children of a person with Dementia are burdened "with the responsibility to act on behalf of the affected parent despite a deep sense of grief and loss," which results in frustration.[18] Our research also revealed that the majority of the caregiving role is carried out by the female family members. Hence, the female caregivers scored higher in strain index compared to the male caregivers. In contrast, male caregivers reported a significantly higher level of resilience. Being a male caregiver has been reported to be positively related to higher caregiver resilience.[15] Research demonstrated that women caregivers mainly adopted emotion-focused strategies and this style is related to a higher level of distress, whereas, male caregivers mainly adopt task-oriented strategies, which is associated with lower distress.[13] Moreover, the cultural expectation associated with family duties which believes that care for elderly should be provided by women may impose extra burden on them.[20] In many Southeast and East Asian societies, the cultural expectation of 'family as caregiver for elderly' is mostly due to the reinforced tradition in younger ages that caregiving is an integral part of life to be carried out with love and sympathy for parents. In addition, formal programs in majority of these countries have very low coverage of older adults,[4] and the lack of adequate formal health care support facilities for older people has forced families to provide support for those affected by AD.[5] Therefore, the policies should focus on providing appropriate interventions to enable Asian families to provide this support.[4]

In spite of the results presented, it should be noted that there are several limitations in this current study. First, the physical and psychological caregiver strain were not differentiated, which may have demonstrated a differential pattern in caregiver strain in this cohort of caregivers. This study included all caregivers, and patients of all stages to allow wider applicability of these results to the clinical setting. However, as in previous studies, the caregivers in this cohort consisted of mostly women, were children to the AD patients and it is acknowledge that specific subgroups may have unique needs. In addition, although the caregiver assessment of the patient was used as an indicator of high caregiver strain, it is recognized that high caregiver strain itself may negatively impact caregiver recipient's health and on caregiver perception of the caregiving tasks. Furthermore, although ADFM is one of largest centers in Malaysia providing care to AD patients and play a major role in educating AD caregivers, there is a need to validate these findings as this is a single-institution, hypothesis-generating study. It is hoped that by identifying caregivers of AD at high risk of caregiver strain, it will allow interventions to be given to those most in need.

Conclusions

The significant negative correlation between resilience level and caregiver strain highlighted the importance of interventions for increasing resilience in AD caregivers. For substantiation of the current findings, future studies addressing the appropriateness of interventions to improve the family caregivers' resilience level, and supports for AD patients to empower them in performing their daily tasks that can reduce the imposed burden on caregivers are required.

Conflict of interest

The authors declare that they have no conflict of interests.

Acknowledgment

This work was supported by International Medical University [project no.: IMU Cares 1/2016 (02)]. Authors would like to thank Alzheimer's Disease Foundation Malaysia (ADFM) who assisted the data collection and to all caregivers of this research study for their contribution and sharing of experiences.

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