



Factors associated with burden among male caregivers for people with dementia

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Abstract

Background: There is a dearth of information on male dementia caregivers in Asia and, in particular, on the factors relating to caregiver burden. We aimed to identify factors that may be associated with burden among male caregivers of people with dementia (PWD).

Methods: Data were collected from a national dementia registration survey. The caregiver burden was measured with the short version of the Zarit Burden Interview (ZBI). We analyzed the correlation between ZBI scores and variables, such as demographic data of PWD and their male caregivers, caregivers' monthly income, the relationship between PWD and caregivers, the severity of dementia, physical comorbidities and activities of daily living (ADL) of PWD, and neuropsychiatric symptoms assessed by the Neuropsychiatric Inventory (NPI).

Results: A total of 509 PWD and their male caregivers were included. The majority of caregivers were sons (72.1%) and husbands (22.0%). Sons had higher ZBI scores than husbands (28.5 ± 15.2 vs 22.0 ± 17.0 ; $p < 0.001$). Multivariable linear regression showed that sons as caregivers ($\beta = 7.44$, $p = 0.034$), ADL ($\beta = 0.52$, $p = 0.002$), and NPI_severity subscore of apathy ($\beta = 2.74$, $p = 0.001$) were positively associated with ZBI scores.

Conclusion: Poor ADL and apathy in PWD and being a patient's son were associated with higher levels of burden among male dementia caregivers. Effective interventions are needed to assist male caregivers in accomplishing their caregiving role and at the same time to alleviate their caregiver burden.

Keywords: Activities of daily living; Caregiving; Men; Neuropsychiatric symptoms

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1. INTRODUCTION

Dementia is a syndrome characterized by impairment in daily activities and a gradual cognitive decline in multiple cognitive domains, including learning and memory, complex attention, executive function, perceptual-motor function, and social cognition.¹ As dementia progresses, people with dementia (PWD) become more dependent, placing physical, emotional, social, and financial demands on their caregivers.² Dementia caregivers carry higher risks for cardiovascular diseases and mental health disorders than the general population,³ and family caregivers of PWD often experience a higher level of burden than caregivers of patients with other chronic illnesses.^{3,4} Due to longer

life expectancy as well as women's higher risk of dementia, the number of male dementia caregivers is expected to rise.⁵ The majority of dementia caregivers are female, but men are providing care for cognitively impaired older adults and PWD at an increasing rate, composing approximately 40% of caregivers in Western countries.^{6,7} According to recent studies in Taiwan, women predominated among dementia caregivers (60% to 65%), and adult children played a major role (63% to 69%) in caring PWD.^{8,9}

Most research on dementia caregiver burden includes more female than male caregivers; therefore, generalizability to the male caregivers is limited.¹⁰⁻¹³ Regarding demographic trends in caregiving shifts, some studies have been conducted to investigate male caregivers in dementia, and they have mostly focused on husbands as caregiver.^{6,14} Studies in Taiwan have found a trend that sons are increasingly serving as family caregivers.¹⁵ However, there is still inadequate understanding about the burden among male caregivers in dementia, especially in Asia, and a lack of research on the caregiving issues of sons.¹⁶ It has been shown that female caregivers tend to report greater levels of burden and mental distress.^{17,18} In contrast, some studies reported a more severe caregiver burden in male than in female caregivers.^{11,19} For example, Conde-Sala et al^{20,21} conducted a series of studies and found that sons reported the highest degree of burden and exhibited the poorest mental health among daughters, wives, and husbands. The inconsistent findings in the literature may partly be because of the heterogeneity of recruited participants, different proportions of the relationship to PWD, and different variables used for adjustment in the analyses. In addition, male caregivers may be unwilling to disclose suffering of burden due to the traditional concept of masculinity that idealizes self-reliance and stoicism.²²

In view of the projected demographic trends and an increased need for male caregivers, it is important to reveal the male experience of dementia caregiving to develop interventions to reduce male caregivers' burden.⁷ We aimed to identify factors that may be associated with burden among male caregivers of PWD by conducting a multicenter cohort study.

2. METHODS

The National Dementia Registry Study in Taiwan (T-NDRS) is a study initiated by the Institute of Population Health Sciences, Taiwan National Health Research Institute, since 2017. Nine hospitals (three in northern Taiwan, two in central Taiwan and four in southern Taiwan) participated in this project. The T-NDRS attempted to investigate the baseline condition (including demographics, cognitive status, and other measures) along with the cognitive and functional changes of PWD and their caregivers' burden. All participants received a clinical interview, neuropsychological assessments, physical and neurological evaluations, laboratory tests (complete blood counts, serum B12 and folic acid, thyroid hormone levels, syphilis serology, and routine biochemical tests), and neuroimaging examinations (computed tomography or magnetic resonance imaging). Dementia was diagnosed according to the respective criteria: (1) NIA-AA criteria for Alzheimer's disease²³; (2) NINDS-AIREN criteria for vascular dementia²⁴; (3) Lund-Manchester criteria for frontotemporal dementia²⁵; (4) 2015 International Dementia with Lewy Bodies conference criteria for dementia with Lewy bodies²⁶; and (5) Movement Disorders Society criteria for dementia due to Parkinson's disease.²⁷ PWD aged between 65 and 90 years had to have a diagnosis of dementia with a Clinical Dementia Rating (CDR) score ≥ 0.5 (covering from very mild to severe dementia) and have at least one main caregiver who frequently took care of/talked to/interacted with PWD for at least 10 hours/wk. The caregiver had to accompany PWD for

the interview. The Ethics Committee and Institutional Review Board of all participating hospitals approved the study. All participating caregivers provided written informed consent.

Only PWD-male caregiver dyads in the T-NDRS database were included and analyzed (Supplementary Fig. 1, <http://links.lww.com/JCMA/A133>). The exclusion criteria were any other central nervous system disease other than dementia, psychosis not due to dementia, a history of alcohol use disorder, hepatic encephalopathy, or an expected life expectancy of less than 6 months. The burden of the dementia caregivers was assessed by using the 22-item, self-report Zarit Burden Interview (ZBI).²⁸ The ZBI is one of the most commonly used instruments for assessing caregiving burden. Each question is scored on a 5-point Likert scale with a total score ranging from 0 (low burden) to 88 (high burden). All caregivers reported the presence of neuropsychiatric symptoms (NPSs) during the last few weeks according to the Neuropsychiatric Inventory Questionnaire (NPI-Q).²⁹ The NPI-Q examined 12 subdomains of behavioral functioning: delusions, hallucinations, agitation/aggression, dysphoria, anxiety, euphoria, apathy, disinhibition, irritability/lability, aberrant motor activity, nighttime behavioral disturbances, and appetite and eating abnormalities. The severity of NPSs was scored on a 3-point scale (1 mild, 2 moderate, and 3 severe). The NPI-distress quantifies the distress experienced by caregivers for individual NPI symptom. The male caregivers were asked to grade their psychological distress on a 6-point scale: 0 (not at all distressing) to 5 (extremely distressing). As NPI-distress was used to measure caregivers' distress relating to specific NPS, the ZBI was used to evaluate burden in general. The cognitive status of PWD was evaluated using the Mini-Mental State Examination (MMSE)³⁰ and CDR scores.³¹ MMSE, a 30-point questionnaire, includes tests of orientation, attention, memory, language, and visual-spatial skills. It is widely used to measure cognitive impairment. CDR is used to assess cognitive and functional performance in six domains: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care. It is widely utilized to grade the severity of dementia with scores that range from 0 (no impairment) to 3 (severe impairment). The patients' activities of daily living (ADL) were assessed using the physical self-maintenance scale.³² The scale measures six activities: toileting, feeding, dressing, grooming, locomotion, and bathing. Higher scores indicate a lower level of function.

2.1. Statistical analysis

Categorical and continuous variables were analyzed and demonstrated by numbers with percentages and means with SDs, respectively. In subgroup analysis of husbands and sons, the chi-square test for categorical variables and independent t-test for continuous variables were used to calculate the differences between the demographics of husbands and sons. ZBI scores representing the extent of caregiver burden were the dependent variables. To evaluate the association between caregiver burden and those variables, a multivariable linear regression model was performed in which β values with 95% confidence intervals (95% CIs) were calculated after adjusting for four different models. Multivariable linear regression model 1 was adjusted for patients' characteristics (age, sex, and education), caregivers' characteristics (age and education), relationship, living together or not, and family income. Model 2 was adjusted for all variables in model 1 plus patients' smoking and drinking habits, patients' cognitive and functional status, age at dementia diagnosis, and dementia subtype. Model 3 was adjusted for all variables in model 2 plus adjusting for patients' physical diseases. Model 4 addressed model 3 plus adjusting for the severity of each NPI item. We further analyzed the association between NPI-distress and independent variables by using the above-mentioned multivariable linear regression model 1 to model 3.

The factor stepwise selection approaches in multivariable linear analyses were also conducted for all participants and subgroup participants (ie, sons and husbands) to evaluate factors that may impact caregiver burden. All statistical analyses were performed using SPSS version 21.0 (IBM, Armonk, NY) with 2-tailed statistical tests. *p* values less than 0.05 were considered statistically significant.

3. RESULTS

A total of 509 PWD with a female predominance and their male caregivers were included, with mean ages of 77.8 and 56.8 years, respectively. The majority of caregivers were sons (72.1%) and husbands (22.0%) of PWD. The caregivers had a higher education level than PWD (13.4 ± 3.8 vs 6.3 ± 4.6 years). The average age at dementia diagnosis for PWD was 75.9 years, and more than half of them were diagnosed with AD (60.7%). The average MMSE score was 15.4 and 1.2 on the CDR (CDR = 1, *n* = 174, 34.2%). The mean ZBI score was 26.9 ± 15.8. Sons as caregiver had higher ZBI scores than husbands as caregiver (28.5 ± 15.2 vs 22.0 ± 17.0; *p* < 0.001). Most caregivers lived with PWD (72.7%) and had earnings in the middle family income class. Each NPI-Q item demonstrated similar averaged severity and distress with the exception of a relatively lower severity and distress of euphoria and a relatively higher severity and distress of sleep/nighttime behavior change (Table 1; Supplementary Table 1, <http://links.lww.com/JCMA/A133>).

In models 1, 2, and 3, the ZBI score was negatively correlated with the highest income class and positively correlated with the

ADL of PWD and the relationship of “PWD-son” (Table 2). Certain dementia subtypes, such as AD and Lewy body dementia, may to some extent impact caregiver burden, but their influence may be easily interfered with by additional variables. Physical diseases, psychiatric disorders, and life habits such as drinking and smoking did not show an influence on the ZBI scores.

In model 4, each NPI_severity item was added to the analysis, and the effect of NPSs on ZBI scores was analyzed (Table 3). The NPI_severity score for the apathy domain was significantly associated with ZBI scores (β : 2.74, 95% CI, 1.12 to 4.37, *p* < 0.001). In the stepwise selection approaches of model 4, ADL (β = 0.50, *p* < 0.001), NPI severity_irritability (β = 2.07, *p* = 0.018), NPI severity_apathy (β = 2.73, *p* < 0.001), caregivers' relationship to PWD (β = 4.44, *p* = 0.002), NPI severity_delusion (β = 1.95, *p* = 0.017), and NPI severity_sleep/nighttime behavior (β = 1.47, *p* = 0.031) showed a significant effect on caregiver burden after adjustment (Table 4).

Multivariable linear regression analyses showed that the CDR and ADL of PWD, diagnosed as having frontotemporal dementia, and having a history of anxiety disorder were positively associated with NPI_distress of male caregivers (Supplementary Table 2, <http://links.lww.com/JCMA/A133>). In the stepwise selection approaches for NPI_distress, CDR (β = 2.48, *p* < 0.001), anxiety (β = 6.80, *p* < 0.001), frontotemporal dementia (β = 8.84, *p* = 0.001), ischemic stroke (β = -4.12, *p* < 0.001), and ADL (β = 0.29, *p* < 0.001) showed a significant effect on NPI_distress after adjustment (Supplementary Table 3, <http://links.lww.com/JCMA/A133>).

Table 1

Demographic data of people with dementia (n = 509) and their caregivers

	Mean (SD)/n (%)		Mean (SD)/n (%)
Patient_Age	77.83 (7.98)	Physical diseases	
Patient_sex, Male	113 (22.2%)	Hypertension	306 (60.1%)
Patient_Education, y	6.3 (4.57)	Diabetes	166 (32.6%)
Caregiver_Age	56.76 (14.08)	Hyperlipidemia	162 (31.8%)
Caregiver_Education, yr	13.44 (3.79)	Ischemic stroke	62 (12.2%)
Relationship		Hemorrhagic stroke	16 (3.1%)
Husbands	112 (22.0%)	Transient ischemic attack	47 (9.2%)
Sons	367 (72.1%)	Head trauma	32 (6.3%)
Other relatives	24 (4.7%)	CAD	10 (2.0%)
Others	6 (1.2%)	Heart failure	26 (5.1%)
Live together, yes	370 (72.7%)	Depression	30 (5.9%)
Family income		Anxiety	20 (3.9%)
<30,000 NTD	125 (24.6%)	NPI_severity	
30,000–100,000 NTD	315 (61.8%)	NPI severity_delusion	0.52 (0.88)
>100,000 NTD	69 (13.6%)	NPI severity_hallucination	0.37 (0.77)
MMSE	15.39 (7.01)	NPI severity_agitation	0.37 (0.75)
CDR	1.17 (0.77)	NPI severity_depression	0.47 (0.81)
ADL	4.28 (5.46)	NPI severity_anxiety	0.42 (0.79)
Drinking, yes	6 (1.2%)	NPI severity_euphoria	0.09 (0.38)
Smoking, yes	14 (2.8%)	NPI severity_apathy	0.55 (0.92)
ZBI score	26.94 (15.84)	NPI severity_disinhibition	0.35 (0.76)
Dementia diagnosis age	75.89 (8.28)	NPI severity_irritability	0.50 (0.86)
Dementia subtype		NPI severity_aberrant	0.38 (0.81)
Alzheimer's disease	309 (60.7%)	NPI severity_sleep/nighttime behavior	0.67 (1.03)
Vascular dementia	66 (13.0%)	NPI severity_appetite	0.33 (0.75)
Mixed dementia	46 (9.0%)		
Frontotemporal dementia	9 (1.8%)		
Lewy body dementia	10 (2.0%)		
Parkinson's disease with dementia	20 (3.9%)		
Unknown type	49 (9.6%)		

ADL = activities of daily living; CAD = coronary artery disease; CDR = clinical dementia rating scale; MMSE = mini-mental state examination; NPI = neuropsychiatric inventory; NTD = new Taiwan dollar; ZBI = Zarit Burden interview.

Table 2
Multivariable linear regressions for ZBI scores of different models

	Model 1		Model 2		Model 3	
	β (95% CI)	<i>p</i>	B (95% CI)	<i>p</i>	β (95% CI)	<i>p</i>
Patient_Age	0.09 (−0.15 to 0.33)	0.447	−0.14 (−0.74 to 0.47)	0.658	−0.06 (−0.68 to 0.55)	0.841
Patient_sex, male	−2.43 (−6.10 to 1.24)	0.194	−2.41 (−6.07 to 1.25)	0.196	−2.31 (−6.03 to 1.42)	0.224
Patient_Education, y	0.31 (−0.05 to 0.68)	0.092	0.32 (−0.05 to 0.69)	0.092	0.30 (−0.08 to 0.68)	0.120
Caregiver_Age	0.01 (−0.20 to 0.20)	0.985	0.01 (−0.18 to 0.21)	0.885	0.01 (−0.19 to 0.20)	0.980
Caregiver_Education, y	0.11 (−0.33 to 0.55)	0.627	0.21 (−0.22 to 0.64)	0.337	0.18 (−0.26 to 0.61)	0.429
Family income						
<30,000 NTD	0.00 (reference)		0.00 (reference)		0.00 (reference)	
30,000–100,000 NTD	−1.26 (−4.60 to 2.08)	0.460	−2.04 (−5.26 to 1.17)	0.213	−2.01 (−5.26 to 1.23)	0.224
>100,000 NTD	−4.92 (−9.76 to −0.08)	0.046	−5.20 (−9.87 to −0.53)	0.029	−5.2 (−9.92 to −0.47)	0.031
Relationship						
Husbands	0.00 (reference)		0.00 (reference)		0.00 (reference)	
Offspring	7.68 (0.54 to 14.82)	0.035	7.42 (0.43 to 14.41)	0.038	7.77 (0.66 to 14.87)	0.032
Other relatives	5.13 (−5.03 to 15.30)	0.322	5.38 (−4.66 to 15.41)	0.293	5.57 (−4.63 to 15.76)	0.284
Others	7.53 (−6.97 to 22.03)	0.308	8.85 (−5.22 to 22.92)	0.217	7.87 (−6.43 to 22.16)	0.280
Live together, yes	0.63 (−2.69 to 3.94)	0.711	−0.09 (−3.28 to 3.11)	0.958	0.11 (−3.13 to 3.36)	0.945
MMSE			−0.22 (−0.50 to 0.06)	0.130	−0.21 (−0.50 to 0.08)	0.147
CDR			0.02 (−2.65 to 2.7)	0.988	−0.18 (−2.92 to 2.56)	0.900
ADL			0.70 (0.37 to 1.04)	<0.001	0.75 (0.41 to 1.08)	<0.001
Drinking, yes			1.82 (−11.81 to 15.45)	0.793	1.82 (−12.36 to 16.00)	0.801
Smoking, yes			0.48 (−8.86 to 9.83)	0.919	0.56 (−8.91 to 10.03)	0.907
Dementia diagnosis sge			0.02 (−0.52 to 0.57)	0.936	−0.04 (−0.60 to 0.52)	0.886
Dementia subtype						
Alzheimer's disease			5.39 (0.63 to 10.15)	0.027	4.81 (−0.10 to 9.72)	0.055
Vascular dementia			1.66 (−4.03 to 7.36)	0.566	3.76 (−2.62 to 10.15)	0.248
Mixed dementia			2.13 (−4.02 to 8.27)	0.497	3.19 (−3.40 to 9.79)	0.342
Frontotemporal dementia			8.35 (−2.68 to 19.39)	0.138	7.15 (−4.08 to 18.38)	0.212
Lewy body dementia			10.63 (0.09 to 21.17)	0.048	9.82 (−0.89 to 20.54)	0.072
Parkinson's disease with dementia			5.02 (−2.93 to 12.97)	0.215	3.85 (−4.25 to 11.95)	0.351
Physical diseases						
Hypertension					−0.87 (−3.82 to 2.07)	0.561
Diabetes					−1.43 (−4.43 to 1.57)	0.349
Hyperlipidemia					1.05 (−2.11 to 4.21)	0.516
Ischemic stroke					−4.05 (−9.39 to 1.29)	0.136
Hemorrhagic stroke					−2.46 (−10.61 to 5.69)	0.553
Transient Ischemic Attack					−1.99 (−7.07 to 3.09)	0.442
Head trauma					−0.81 (−6.40 to 4.78)	0.775
CAD					2.05 (−5.29 to 9.40)	0.583
Heart failure					−5.49 (−15.35 to 4.38)	0.275
Depression					2.29 (−5.07 to 9.64)	0.542
Anxiety					0.66 (−6.17 to 7.50)	0.849
ΔR^2		0.046		0.104		0.011
<i>P</i>		0.014		<0.001		0.869

Bold type indicated statistical significance.

ADL = activities of daily living; CAD = coronary artery disease; CDR = clinical dementia rating scale; MMSE = mini-mental state examination; NPI = neuropsychiatric inventory; NTD = new Taiwan dollar; ZBI = Zarit Burden interview.

In subgroup analyses, the spousal caregivers (husbands, $n = 112$) had a mean age of 76 years, an average education level of 10.9 years, and an average ZBI score of 22.0. They cared for PWD with a mean age of 73 years, an average education level of 8.0 years, a mean MMSE score of 16.8, a mean CDR score of 1.2, and a Barthel ADL score of 3.3. On the other hand, the offspring caregivers (son, $n = 367$) had an average age of 51.7 years, an education level of 14.2 years, and a mean ZBI score of 28.5. They cared for PWD with a mean age of 79.3 years, an average education level of 5.9 years, a mean MMSE score of 14.9, a mean CDR score of 1.2, and a mean Barthel ADL score of 4.6. For husbands, factors such as apathy, anxiety, euphoria, and poor ADL of PWD increased their care burden, and factors such as living with PWD and patients with cardiovascular diseases decreased the caregiver burden. With regard to sons,

poor ADL, irritability, delusion, and nighttime behavior of PWD significantly enhanced their caregiver burden (Table 5).

4. DISCUSSION

To our knowledge, this is the first study to investigate factors that may be associated with burden among male dementia caregivers in Asia. In this study, we found that poor ADL, the NPS of apathy, and being a patient's son were associated with more caregiver burden after adjusting for medical comorbidities, education, dementia subtypes, and other demographic variables. We also found an inverse association between male caregiver burden and monthly income. Furthermore, poor ADL and more NPSs of PWD may lead to higher levels of burden for both husbands and sons.

Table 3
Multivariable linear regressions for ZBI scores with adjustment of NPI scores

	Model 4 (NPI_severity)	
	β (95% CI)	<i>p</i>
Patient_Age	0.06 (−0.54 to 0.66)	0.843
Patient_sex, male	−2.09 (−5.71 to 1.53)	0.256
Patient_Education, y	0.29 (−0.07 to 0.66)	0.118
Caregiver_Age	0.01 (−0.18 to 0.20)	0.932
Caregiver_Education, y	0.12 (−0.30 to 0.54)	0.570
Family income		
<30,000 NTD	0.00 (reference)	
30,000–100,000 NTD	−1.35 (−4.50 to 1.80)	0.399
>100,000 NTD	−3.72 (−8.33 to 0.89)	0.113
Relationship		
Husbands	0.00 (reference)	
Offspring	7.44 (0.58 to 14.31)	0.034
Other relatives	5.62 (−4.18 to 15.42)	0.260
Others	7.26 (−6.56 to 21.08)	0.303
Live together, yes	0.29 (−2.83 to 3.41)	0.855
MMSE	−0.24 (−0.52 to 0.04)	0.098
CDR	−1.70 (−4.39 to 0.99)	0.215
ADL	0.52 (0.19 to 0.86)	0.002
Drinking, yes	4.86 (−8.75 to 18.47)	0.483
Smoking, yes	0.93 (−8.19 to 10.05)	0.842
Dementia diagnosis age	−0.15 (−0.7 to 0.39)	0.576
Dementia subtype		
Alzheimer's disease	3.58 (−1.18 to 8.33)	0.140
Vascular dementia	2.46 (−3.70 to 8.61)	0.433
Mixed dementia	2.50 (−3.87 to 8.87)	0.441
Frontotemporal dementia	1.33 (−9.83 to 12.49)	0.815
Lewy body dementia	7.52 (−2.89 to 17.93)	0.157
Parkinson's disease with dementia	3.76 (−4.09 to 11.62)	0.347
Physical diseases		
Hypertension	−1.29 (−4.14 to 1.55)	0.372
Diabetes	−1.71 (−4.64 to 1.22)	0.252
Hyperlipidemia	1.52 (−1.53 to 4.58)	0.328
Ischemic stroke	−1.36 (−6.54 to 3.82)	0.605
Hemorrhagic stroke	−1.09 (−8.93 to 6.76)	0.786
Transient ischemic attack	−1.63 (−6.54 to 3.27)	0.514
Head trauma	−1.03 (−6.41 to 4.36)	0.708
CAD	0.53 (−6.54 to 7.60)	0.883
Heart failure	−7.93 (−17.58 to 1.73)	0.107
Depression	−0.05 (−7.35 to 7.26)	0.990
Anxiety	−2.65 (−9.43 to 4.14)	0.444
NPI_severity		
NPI_delusion	1.52 (−0.28 to 3.32)	0.098
NPI_hallucination	0.43 (−1.73 to 2.58)	0.696
NPI_agitation	1.82 (−0.47 to 4.11)	0.119
NPI_depression	−0.34 (−2.43 to 1.75)	0.751
NPI_anxiety	1.88 (−0.29 to 4.04)	0.089
NPI_euphoria	−1.56 (−5.23 to 2.11)	0.404
NPI_apathy	2.74 (1.12 to 4.37)	0.001
NPI_disinhibition	0.37 (−1.89 to 2.63)	0.749
NPI_irritability	0.63 (−1.60 to 2.86)	0.577
NPI_aberrant	−0.79 (−2.88 to 1.31)	0.462
NPI_night	1.36 (−0.16 to 2.87)	0.079
NPI_appetite	0.86 (−1.03 to 2.74)	0.372
ΔR^2		0.093
<i>P</i>		<0.001

Bold type indicated statistical significance.

ADL = activities of daily living; CAD = coronary artery disease; CDR = clinical dementia rating scale; MMSE = mini-mental state examination; NPI = neuropsychiatric inventory; NTD = new Taiwan dollar; ZBI = Zarit Burden interview.

Table 4
Multivariable linear regression in a stepwise manner

Variables	β (95% CI)	<i>p</i>
ADL	0.50 (0.26 to 0.75)	<0.001
NPI severity_irritability	2.07 (0.36 to 3.78)	0.018
NPI severity_apathy	2.73 (1.26 to 4.20)	<0.001
Caregiver relationship: son vs husband	4.44 (1.64 to 7.25)	0.002
NPI severity_delusion	1.95 (0.35 to 3.55)	0.017
NPI severity_sleep/nighttime behavior	1.47 (0.14 to 2.81)	0.031

ADL = activities of daily living; NPI = neuropsychiatric inventory.

We found that sons had higher levels of caregiver burden than husbands and that sons as caregivers were an independent factor relating to higher caregiver burden. The majority of the male caregivers in our data were sons (72.1%), indicating an increase compared to 30% in another cohort two decades ago.³³ The responsibility of caring wives with dementia would provide husbands a unique role, which gives meaning and purpose to their late life.³⁴ In contrast, sons of PWD would have to overcome the hurdle of accepting their new roles as care providers. Compared to spousal caregivers, offspring caregivers tend to have to make more lifestyle adjustments or try to reconcile multiple roles and responsibilities.^{20,21} Also, adult children would need to allocate time for caregiving responsibilities, jobs, their own family and pursuit of leisure activities, which might cause greater stress.³⁵ It is of interest to note that gender differences may have implications on caregiver feelings of burden: women are more emotionally focused and connected in relationship, while men focus on tasks.³⁶ How gender differences of stress coping strategies impact caregivers' perceived burden require investigation. In addition, cultural background in different countries should also be taken into consideration. In Asia, filial piety has been traditionally viewed as a central value, in which elderly individuals are to be respected and obligatory care is required.

Subanalyses demonstrated that husbands and sons as caregiver may respond disparately to different NPIs in PWD (Table 5). Husbands as dementia caregiver may suffer from more distress if PWD have more severe apathy. Older men had been suggested to have smaller social networks, and wives are often the only intimate friends they have.³⁷ In an older spousal caregiver study, husbands of PWD seemed to be more concerned about being abandoned by their wives.³⁸ In our study, living together with wives with dementia was associated with lower caregiver burden among husbands, corresponding to our finding that apathy of wives caused burden

Table 5
Factors analysis of caregiver burden between husband and son in multivariable linear regressions by the stepwise manner

Relationship: husband (n = 112)	β (95% CI)	<i>p</i>
NPI severity_apathy	7.53 (4.63 to 10.43)	<0.001
NPI severity_anxiety	3.66 (0.12 to 7.21)	0.043
ADL	0.52 (0.03 to 1.00)	0.037
Cardiovascular diseases	−16.28 (−30.14 to −2.42)	0.022
NPI severity_euphoria	9.83 (0.85 to 18.81)	0.032
Lived together with PWD, yes	−28.57 (−55.85 to −1.29)	0.040
Relationship: son (n = 367)		
ADL	0.46 (0.18 to 0.74)	0.001
NPI severity_irritability	2.85 (0.92 to 4.79)	0.004
NPI severity_delusion	2.26 (0.49 to 4.04)	0.013
NPI severity_sleep/nighttime behavior	1.76 (0.17 to 3.35)	0.030

ADL = activities of daily living; NPI = neuropsychiatric inventory; PWD = people with dementia.

to husbands and providing evidence for the emotional attachment between spouses. In contrast, sons as dementia caregiver had a higher burden when PWD had more irritability and delusions. Conde-Sala et al²¹ reported a similar finding that irritability in dementia was associated with caregiver burden in a daughter-predominant offspring group. Taken together, these findings suggest that NPSs are important factors affecting psychological and physical burden among male dementia caregivers.

ADL impairment in PWD was found to be associated with higher caregiver burden and NPI_distress in our study. Two qualitative studies using focus groups and in-depth interviews showed that husbands of people with AD have the burden of being inexperienced food providers. They found that husbands were concerned about food preparation and meeting patients' nutritional needs.^{39,40} However, the two studies only enrolled patients' husbands but not sons. Among sons as caregivers, we demonstrated that ADL impairment in PWD was the factor significantly related to caregiver burden in a stepwise regression model ($p = 0.001$). Caregivers, as either husbands or sons, need to face the challenge of caring for patients' ADL. Instructions in food preparation, cooking experience, and other care skills should be provided by the long-term care system to support male dementia caregivers.

We found that NPSs of dementia were positively associated with male caregiver burden, even after controlling for the severity of dementia. For individual NPSs, apathy correlated with increased male caregiver burden. Apathy, characterized by diminished motivation in goal-directed behaviors or cognitive activity, indifference, low social engagement, and blunted emotional response, is one of the most common NPSs among PWD.⁴¹ The lack of motivation in performing activities hinder the rehabilitation of these patients⁴²; caregivers reported emotionally distant relationships with PWD with apathy, which was similarly faced by both spouses and adult children.⁴³ The burden of the caregiver of apathetic patients may be explained by the greater disability of these patients and by the caregivers' feeling of frustration.⁴⁴ Previous research with predominantly female participants confirmed that apathy in PWD caused distress to their caregivers.⁴⁵ We also found influence of nighttime behavior disturbance on male caregiver burden. Nighttime behavioral disturbances in dementia, such as wandering and getting up repeatedly during the night, cause stress to caregivers and often lead to patients' institutionalization.⁴⁶

Along with the worsening of dementia, the time needed for assistance in ADL and supervision increases.⁴⁷ In addition to the increased physical dependence and NPS of PWD, the great number of hours needed for direct care for PWD is also an indicator of caregiver burden.⁴⁸ We did not collect information about the time male caregivers spent on dementia care, which should be included in future research. Family caregivers tend to sacrifice their leisure pursuits, to restrict time with friends and family, and to give up employment or to reduce time in work. In Taiwan, adult children played a major role in caring parents with dementia, and 50% of them are employed.⁴⁹ Employed family caregivers of PWD who had more working hours had less work efficiency, decreased ability to balance work and caregiving demands, and poorer quality of life and mental health.⁵⁰ Psychosocial and educational interventions aimed at managing the time spent on care may alleviate the burden of dementia caregivers.

Higher monthly income of the caregivers was found to be associated with lower levels of caregiver burden in our study. Family caregivers commonly experience financial strain, both when PWD are cared for at home and in an institution, as a consequence of providing care during the long course of the dementia.⁵¹ Studies of Western subjects have found that caregivers with fewer financial resources had reduced quality of life, higher risk of depression, and more caregiver burden than caregivers with higher income.^{52,53} Caregivers with higher financial

resources probably have more access to healthcare services that may reduce caregiver burden⁵²; therefore, sufficient social support to male caregivers from the long-term care resources could reduce their caregiver burden.^{8,54} In response to the aging trend, the tax-based long-term care Act 2.0 (LTC 2.0) was launched in 2016. The policy provides home- and community-based health-care service, and the government performed programs including "dementia integrated care centers" and "community dementia care centers," providing cognitive enhancement programs, respite care, and caregiver support groups. Caregivers' feelings about receiving assistance from LTC services and the effect of LTC 2.0 services in reducing caregiver burden are still not clear. We did not collect information about LTC service use from the male caregivers in this study. Investigations in the influence of the LTC 2.0 utilization on the well-being of PWD and their caregivers are need in the future, so as to provide evidence for the modification of the LTC programs.

This study has several limitations. First, information on other potential factors contributing to caregiver burden, such as family functioning, current relationship quality, premorbid relationship satisfaction, caregiver's health condition, and male caregiver's marital status, was not collected.^{21,55-57} Therefore, the identification of the factors may be biased. Second, the sample size in certain dementia subtypes, such as frontotemporal dementia, Lewy body dementia, and Parkinson's disease with dementia, is small. Future studies could recruit more participants to produce findings with higher statistical power. Third, we used a cross-sectional study design, and causal links cannot be inferred. Last, most of the participating hospitals were medical centers; therefore, our findings may not be generalizable to those visiting community clinics or those not seeking medical help.

This study provided evidence as to factors relating to the burden of male dementia caregivers. Our results could be considered important guidance for policymaking, for example, in-home service for ADL and the management of NPSs. Effective interventions are needed to assist male caregivers in accomplishing their caregiving role and at the same time to alleviate their caregiver burden.

APPENDIX A. SUPPLEMENTARY DATA

Supplementary data related to this article can be found at <http://links.lww.com/JCMA/A133>.

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