Archives of Gerontology and Geriatrics 81 (2019) 25–30

Contents lists available at ScienceDirect

Archives of Gerontology and Geriatrics

journal homepage: www.elsevier.com/locate/archger

Activities of daily living function and neuropsychiatric symptoms of people with dementia and caregiver burden: The mediating role of caregiving hours

Chung-Ying Lin[a], Pei-Yu Shih[c], Li-Jung Elizabeth Ku[b],*

[a] *Department of Rehabilitation Sciences, Faculty of Health and Social Sciences, The Hong Kong Polytechnic University, Hung Hom, Hong Kong*
[b] *Department of Public Health, National Cheng Kung University Hospital, College of Medicine, National Cheng Kung University, Tainan, Taiwan*
[c] *ESH (Environment Safety and Health) Management Department, Innolux Corporation, Tainan, Taiwan*

ARTICLE INFO

Keywords:
Dementia
Activities of daily living (ADL)
Neuropsychiatric behaviors
Caregiving hours
Caregiver burden

ABSTRACT

Objective: Due to the presence of neuropsychiatric behaviors and the decreased ability for activities of daily living (ADLs), family caregivers experience high burden levels in caring for people with dementia (PWD). This study sought to test the mediating role of caregiving hours in association with PWDs' ability for basic activities of daily living (BADL) function or neuropsychiatric behaviors and caregiver burden.
Methods: This study used two waves of survey data, collected between 2013 and 2016, from 186 PWD–caregiver dyads in a dementia clinic at a teaching hospital in southern Taiwan. Two sets of multiple linear regression models were used to analyze the relationships between the changes in patients' BADL function, patients' neuropsychiatric behaviors, caregiving hours in ADL (including BADL and Instrumental ADL), and caregiver burden (measured using Zarit Burden Interview). Bootstrapping methods were used to detect the mediating effects of caregiving hours in ADL if the 95% confidence interval (CI) did not cover 0.
Results: Caregiving hours in BADL mediated the relationship of PWDs' BADL function and caregiver burden (effect = −0.0137, 95% bootstrap CI = −0.0379, −0.0003). However, such mediating effects were not found in the relationship of PWDs' neuropsychiatric behaviors and caregiver burden.
Conclusions: In order to relieve caregiver burden, respite care services for caregivers for PWD should target services that assist with PWD's BADL.

1. Introduction

Given that most developed countries are encountering the issue of an ageing or aged society, successful or healthy ageing is important for older populations globally (Atlantis, Browning, & Kendig, 2010). Unfortunately, dementia is a significant obstacle that prevents 5–7% of the global older population from healthy ageing (Prince et al., 2013). In addition to the cognitive impairment, people with dementia (PWD) have neuropsychiatric behaviors (Lyketsos et al., 2011) and decreased ability in activities of daily living (ADL), including basic ADL (BADL) and instrumental ADL (IADL) (Giovannetti, Thomas, & Marcotte, 2010). BADL refers to the tasks related to self-care, such as bathing and functional mobility (Mahoney & Barthel, 1965). IADL indicates the tasks not necessary for fundamental functioning; instead, it relates more to a person's ability to independently live in a community, such as money management and meal preparation (Lawton & Brody, 1969).

Due to the presence of neuropsychiatric behaviors and the decreased ability in ADL, caregivers experience high burden levels in caring for a family member with dementia (Bergvall et al., 2011; Chappell & Reid, 2002; van der Lee, Bakker, Duivenvoorden, & Dröes, 2014). Moreover, particular attention should be given to burden of a family caregiver (hereafter referred to as caregiver) because: (1) caregiver burden may jeopardize the health of the caregivers; (2) caregivers may be unable to effectively collaborate with healthcare professionals due to the burden; and, (3) caregivers may experience burnout due to the burden and stop providing care for PWD (Chang, Su, & Lin, 2016; Lin, Wang, Pai, & Ku, 2017; Schreiner, Morimoto, Arai, & Zarit, 2006).

To our best knowledge, the mechanism by which neuropsychiatric behaviors and decreased ADL function lead to increased caregiver burden remains unclear. Understanding this mechanism may provide guidance for healthcare professionals to more effectively decrease the caregiver burden for those who care for PWD. Moreover, because it is impossible to *cure* dementia, a neurodegenerative disease (Giovannetti et al., 2010), healthcare professionals are unable to *improve* the

---

* Corresponding author at: Department of Public Health, National Cheng Kung University Hospital, College of Medicine, National Cheng Kung University, No, 1, University Road, Tainan, Taiwan.
E-mail address: eljku@mail.ncku.edu.tw (L.-J.E. Ku).

https://doi.org/10.1016/j.archger.2018.11.009
Received 30 March 2018; Received in revised form 15 November 2018; Accepted 16 November 2018
Available online 17 November 2018

neuropsychiatric behaviors or impaired ADL function, although they may be *maintained*. One potential method to reduce caregiver burden is to provide respite care service (Varela, Varona, Anderson, & Sansoni, 2011). Accordingly, studying the aforementioned mechanism may provide insight for the design of tailored respite care service.

In order to test the underlying mechanism, we simplified the Stress Process Model (SPM) proposed by Pearlin (Pearlin, Mullan, Semple, & Skaff, 1990) and by Yates (Yates, Tennstedt, & Chang, 1999). That is, we proposed and tested the mediating role of caregiving hours after controlling several confounders (e.g., PWD's age, sex, and severity) associated with the PWD's physical or neuropsychiatric functions and caregiver burden. Specifically, our simplified SPM retains the following factors derived from the original SPM: background information (treated as the confounding variables); primary stressors, including ADL functions and neuropsychiatric behaviors (treated as the independent variables); primary appraisal of time in informal care (treated as the mediator); and, caregiver burden (treated as the outcome). While we could not change PWD's conditions, lowering caregiving hours could be one way to reduce caregiver burden if time in informal care was found to be a mediator. Furthermore, by separating caregiving hours into caregiving for PWD's BADL and caregiving for PWD's IADL, our study could also address the question of which approach respite care service should emphasize more, namely PWD's BADL or IADL.

We conducted a longitudinal study using two waves of surveys of dementia caregivers to examine the mediating role of caregiving hours provided by family caregivers to PWD. First, we investigated the association between the *changes* in BADL function and neuropsychiatric behaviors among PWD, caregiving hours provided by family caregivers, and caregiver burden. Second, we examined the temporal associations between the *changes* based on the simplified SPM to identify whether mediating effects exist.

2. Methods

2.1. Participants and procedure

We recruited 286 community-dwelling PWD–caregiver dyads from a dementia clinic of a national university hospital in southern Taiwan. Ethics approval was obtained from the National Cheng Kung University Hospital Institutional Review Board for the Protection of Human Subjects (IRB No: B-ER-102-173). The inclusion criteria required that PWD were diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) criteria (American Psychiatric Association, 1994) and had a family caregiver. Data were collected using telephone interviews with family caregivers older than 18 years of age and had been providing care for at least one year. A detailed description of the study's baseline interview, conducted between November 2013, and April 2015, was previously published (Ku, 2016). Caregivers who participated in the first wave were contacted by our research team for a follow-up interview between November 2015, and June 2016. Although there were 286 PWD–caregiver dyads in the first wave, the second wave included only 186 dyads, because some PWD had either died after the first wave or moved into an institution, or some caregivers declined to participate or could not be reached in the follow-up survey (dropped-out rate: 35%). This study included all caregivers who completed both surveys, so the final sample size was 186 with the average time span between the baseline and the follow-up being 20 months.

2.2. Instruments

2.2.1. Zarit burden interview (ZBI)

The ZBI is a commonly used questionnaire for caregivers to self-assess their caregiver burden. The original ZBI contains 22 items rated on a five-point Likert scale (0 = *not at all*; 4 = *extremely*), and different versions of the ZBI have been suggested (Lin, Wang et al., 2017). In this study, we used a 12-item version of the ZBI because its uni-dimensionality and measurement invariance across educational levels and gender have been supported in Taiwan (Lin, Ku, & Pakpour, 2017). We summed the 12-item ZBI (score range = 0–48) to illustrate caregiver burden, where a higher score indicates a heavier burden.

2.2.2. Barthel index (BI)

Functional status was measured with the 10-item BI to assess PWDs' limitations in various BADLs, including grooming, bathing, feeding, toilet use, ascending and descending stairs, dressing, controlling bowel movements, bladder control, moving from a wheelchair to bed and returning, and walking on a level surface (Hsueh, 2001; Mahoney & Barthel, 1965). The total BADL score ranges from 0 to 100, with higher scores indicating less need for support.

2.2.3. Neuropsychiatric inventory (NPI)

The NPI was used to estimate both the severity and frequency of a wide range of behavioral psychological symptoms, including agitation, depression, and disinhibition (Cummings, 1994). The total NPI score ranges from 0 to 120, where a higher score indicates greater impairment.

2.2.4. Dementia severity

The severity of dementia was assessed by the Clinical Dementia Rating Scale (CDR) (Hughes, Berg, Danziger, Coben, & Martin, 1982) or the Chinese version of the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975), depending on which one was available in the PWD's medical records. PWD were categorized into three stages of severity based on the following criteria consistent with Taiwan's National Health Insurance reimbursement rule for dementia drugs (Bureau of National Health Insurance, 2013): mild dementia ($CDR = 1$ or $MMSE > = 15$), moderate dementia ($CDR = 2$ or $10 < = MMSE < = 14$), severe dementia ($CDR = 3$ or $MMSE < 10$). But for those with fewer than six years of education, the cut-off points of moderate and severe dementia were reduced to $MMSE < = 11$ and $MMSE < = 8$, respectively, due to the effects of education on MMSE performance (Li, Jia, & Yang, 2016).

2.2.5. Caregiving hours in ADL

The quantity of caregiving (hours per week) was calculated by multiplying the number of days per week by the caregiving hours per day. The frequency of caregiving per week was reported directly as the usual number of days per week using the following question: "In a typical week, about how many days do you (caregiver) spend with (him/her) per week?". Three specific questions according to the Resource Utilization in Dementia (RUD) instrument were then employed to estimate how many hours the caregiver spent per day for each type of caregiving activity, namely assistance with BADL, IADL, and supervision for the persons with dementia (Wimo et al., 2013). We also asked the caregiver to report the number of PWD sleep hours so that the total maximum caregiving hours would not exceed 24 minus the time for sleep.

2.2.6. Economic status

The caregiver and the care recipient's household economic status was measured in a survey question asking whether the family had difficulty with monthly expenses. This question was divided into three categories: good (have more than enough money); fair (have enough money); and, poor (have difficulty with expenses).

2.3. Data analysis

In addition to the descriptive statistics performed using frequency (for categorical variables) and mean (for continuous variables), we constructed two sets of multiple linear regression models to understand the relationships between the *changes* in the following variables: PWD's

BADL function (measured using BI); PWD's neuropsychiatric behaviors (measured using NPI); caregiving hours provided by caregivers in ADL (including BADL and IADL); and, caregiver burden (measured using ZBI). The *changes* were assessed using the variable scores at wave 1 minus those scores at wave 2. In addition to using the difference scores to detect *changes*, we carried out several linear mixed-effects models to handle *changes* in another perspective. Moreover, the restricted maximum likelihood estimation was used in the linear mixed-effects models. All regression and linear mixed-effects models controlled the following covariates: PWD's characteristics, including age, sex, and severity of dementia; and caregivers' characteristics, including age, sex, educational level, marital status, duration in caregiving, living status, and economic status.

After constructing the regression models, we used bootstrapping methods with 5000 repeated samples to detect the mediating effects of caregiving hours for both BADL and IADL; a mediating effect was confirmed if the 95% CI of the bootstrapping method did not cover 0 (Lin & Tsai, 2016; Montoya & Hayes, 2017).

All statistical measures were performed using SPSS 23.0 (IBM Corp., Armonk, NY.), while the mediating effects were calculated using PROCESS macro developed by Dr. Hayes (Montoya & Hayes, 2017; Preacher & Hayes, 2004).

3. Results

Table 1 demonstrates the characteristics for both PWD and their caregivers (N = 186). The mean (SD) age for PWD was 77.98 (8.99), and nearly two thirds (60.8%) were female. The severity of dementia was almost equally distributed into three levels: mild (37.1%), moderate (34.9%), and severe (28.0%). Most of the PWD had been diagnosed as having Alzheimer's disease (88.7%), with only a few being considered as early onset (9.7%). The mean age (SD) for caregivers was 59.95 (13.43), and slightly more than two thirds (67.7%) were female. Most of the caregivers were currently married (82.8%), and their relationship with the PWD included spouse (39.2%), sibling (2.2%), adult child (45.2%), and adult child-in-law (13.2%). Almost all the caregivers were the main caregivers (94.6%), of which nearly three fourths were living with the PWD (74.7%). The average duration (SD) of caregiving was 6.72 (3.52) years.

Table 1
Characteristics for PWD and their caregivers (N = 186).

PWD	
Baseline age (year); Mean ± SD	77.98 ± 8.99
Sex (male); n (%)	73 (39.2)
Severity (mild); n (%)	69 (37.1)
Severity (moderate); n (%)	65 (34.9)
Severity (severe); n (%)	52 (28.0)
Diagnosis (Alzheimer's disease); n (%)	165 (88.7)
Early onset (yes); n (%)	18 (9.7)
Baseline Barthel index score; Mean ± SD	75.08 ± 30.63
Baseline neuropsychiatric inventory score; Mean ± SD	17.70 ± 18.10
Follow-up Barthel index score; Mean ± SD	63.67 ± 35.20
Follow-up neuropsychiatric inventory score; Mean ± SD	17.08 ± 18.21
Caregivers	
Baseline age (year); Mean ± SD	59.98 ± 13.43
Sex (male); n (%)	60 (32.3)
Main caregiver (yes); n (%)	176 (94.6)
Education (junior high or below); n (%)	54 (29.0)
Education (senior high); n (%)	69 (37.1)
Education (above senior high); n (%)	63 (33.9)
Marital status (married); n (%)	154 (82.8)
Relationship with PWD (spouse); n (%)	73 (39.2)
Relationship with PWD (sibling); n (%)	4 (2.2)
Relationship with PWD (child); n (%)	84 (45.2)
Relationship with PWD (child-in-law); n (%)	25 (13.2)
Duration of caregiving (month); Mean ± SD	80.64 ± 42.43
Living together (yes); n (%)	139 (74.7)
Economic status (good); n (%)	45 (24.2)
Economic status (fair); n (%)	95 (51.1)
Economic status (poor); n (%)	44 (23.6)
Baseline caring time in BADL per day (hours); Mean ± SD	0.87 ± 1.21
Baseline caring time in IADL per day (hours); Mean ± SD	2.35 ± 1.36
Baseline Zarit burden interview score; Mean ± SD	16.88 ± 9.95
Follow-up caring time in BADL per day (hours); Mean ± SD	0.79 ± 1.48
Follow-up caring time in IADL per day (hours); Mean ± SD	2.50 ± 2.04
Follow-up Zarit burden interview score; Mean ± SD	17.01 ± 11.95

BADL = basic activities of daily living; IADL = instrumental activities of daily living.

The first set of regression models tested the mediating effects of caregiving hours in ADL (including BADL and IADL) in association with the PWD's BI scores and the caregiver burden (Table 2; Models 1, 3, and 5). The results showed that the change of the PWD's BI score was negatively correlated with the change of caregiving hours for BADL (Model 1) and positively correlated with the change of caregiving hours for IADL (Model 3). Moreover, the changes in caregiving hours for BADL and IADL were positively associated with the change in caregiver burden, while the change of BI score was not correlated with the change in caregiver burden (Model 5).

The second set of regression models tested the mediating effects of caregiving hours for ADL in association with the PWD's NPI scores and the caregiver burden (Table 2, Models 2, 4, and 6). The results showed that the change in PWD's NPI scores was positively correlated with the change in the caregiving hours for BADL (Model 2), but was not correlated with the change in caregiving hours for IADL (Model 4). Moreover, the changes in caregiving hours for BADL and NPI were positively associated with the change in caregiver burden, while the change in caregiving hours for IADL was not correlated with the change in caregiver burden (Model 6).

Similar results were found in our linear mixed-effects models: the change of the PWD's BI score was negatively correlated with the change of caregiving hours for BADL (Table 3; Model 1) and positively correlated with the change of caregiving hours for IADL (Table 3; Model 3). The changes in caregiving hours for BADL and IADL were positively associated with the change in caregiver burden, while the change of BI score was not correlated with the change in caregiver burden (Table 3; Model 5). The change in PWD's NPI scores was positively correlated with the change in the caregiving hours for BADL (Table 3; Model 2), and that in caregiving hours for IADL (Table 3; Model 4). The changes in caregiving hours for ADL (including both BADL and IADL) and NPI were positively associated with the change in caregiver burden (Table 3; Model 6). Table 4 further compares the findings between regression models and linear mixed-effects models.

Based on the bootstrapping results shown in Table 5, we found that caregiving hours for BADL was a mediator in the association with BI score and caregiver burden (95% CI = −0.0379, −0.0003), but not in the association with NPI score and caregiver burden (95% CI = −0.0015, 0.0475). Furthermore, the caregiving hours in IADL was not a mediator in the association with the BI (or NPI) score and caregiver burden.

4. Discussion

Our results partially support the simplified SPM: caregiving hours in PWD's BADL mediated the temporal association of PWD's BADL function and caregiver burden. Previous studies have shown that PWD's poor BADL function was associated with increased caregiving hours (Kim, Chang, Rose, & Kim, 2012; van der Lee et al., 2014), and our results also echoed the literature in finding that neuropsychiatric behaviors were positively associated with caregiver burden (Bergvall et al., 2011). In order to provide comprehensive and robust evidence for the mediating role of caregiving hours for caregivers of PWD, we have analyzed both multiple linear regression models using change scores (Table 2) and linear mixed-effect models (Table 3). Results from both

Table 2
Multiple linear regression models explaining caregiving hours for basic activities of daily living (BADL), instrumental activities of daily living (IADL) and caregiver burden.

	Coefficient (SE)					
	DV: Caregiving hours for BADL[a]		DV: Caregiving hours for IADL[a]		DV: Caregiver burden[a]	
	Model 1 ($R^2 = 0.15$)	Model 2 ($R^2 = 0.14$)	Model 3 ($R^2 = 0.15$)	Model 4 ($R^2 = 0.12$)	Model 5 ($R^2 = 0.16$)	Model 6 ($R^2 = 0.22$)
Caregiving hours for BADL[a]	–	–	–	–	1.500 (0.529) **	1.424 (0.519) **
Caregiving hours for IADL[a]	–	–	–	–	0.724 (0.352) *	0.543 (0.333)
Neuropsychiatric Inventory[a]	–	0.011 (0.005) *	–	0.008 (0.008)	–	0.137 (0.036) **
Barthel Index score[a]	−0.009 (0.005) *	–	0.014 (0.007) *	–	−0.041 (0.032)	–
PWD age	−0.007 (0.013)	0.001 (0.012)	0.030 (0.019)	0.034 (0.019)	−0.022 (0.084)	−0.012 (0.083)
PWD sex (Ref: female)	0.177 (0.238)	0.176 (0.230)	−0.378 (0.358)	−0.407 (0.360)	1.389 (1.601)	1.548 (1.536)
PWD severity	0.022 (0.136)	0.069 (0.127)	−0.259 (0.204)	−0.337 (0.197)	−1.200 (0.912)	−0.050 (0.846)
Caregiver sex (Ref: female)	−0.306 (0.252)	−0.302 (0.240)	−0.737 (0.379)	−0.471 (0.374)	2.563 (1.709)	2.516 (1.602)
Caregiver age	−0.023 (0.011) *	−0.023 (0.010) *	−0.014 (0.016)	−0.015 (0.016)	−0.065 (0.071)	−0.073 (0.069)
Caregiver education (Ref: ≤ junior high)	−0.302 (0.266)	−0.340 (0.260)	0.363 (0.400)	0.302 (0.406)	1.024 (1.759)	0.189 (1.737)
Caregiver marital status (Ref: married)	0.026 (0.332)	−0.065 (0.322)	−0.399 (0.499)	−0.463 (0.502)	−2.516 (2.227)	−2.823 (2.138)
Duration in caregiving	0.004 (0.003)	0.004 (0.002)	0.010 (0.004) *	0.011 (0.004) **	0.003 (0.017)	0.004 (0.017)
Living status (Ref: separated)	0.133 (0.266)	0.059 (0.260)	1.011 (0.399) *	1.054 (0.406) *	1.479 (1.811)	1.868 (1.758)
Good economic status (Ref: fair)	−0.505 (0.250) *	−0.435 (0.242)	−0.459 (0.375)	−0.217 (0.378)	−2.939 (1.695)	−2.618 (1.619)
Poor economic status (Ref: fair)	−0.427 (0.255)	−0.535 (0.247) *	0.081 (0.383)	0.147 (0.386)	0.104 (1.722)	−0.620 (1.661)

DV = dependent variable.

Models 1 and 3 did not include caregiving hours for BADL, caregiving hours for IADL, and Neuropsychiatric Inventory score; Models 2 and 4 did not include caregiving hours for BADL, caregiving hours for IADL, and Barthel Index score; Models 5 and 6 did not include Neuropsychiatric Inventory and Barthel Index scores, respectively.

[a] These variable scores represent *changed performance* because they were calculated using wave 2 scores minus wave 1 scores.

* $p < 0.05$.

** $p < 0.01$.

models were nearly identical except for two associations (NPI score and caregiving hours for IADL; caregiving hours for IADL and caregiver burden). Specifically, the regression models did not find the aforementioned associations in the change scores (i.e., change in NPI scores, change in caregiving hours for IADL, and change in caregiver burden). In contrast, the linear mixed-effect models demonstrated the two associations in positive directions. Therefore, we are confident that caregiving hours for BADL is an important factor in caregiver burden. However, the effect of caregiving for IADL hours on caregiver burden was inconsistent between the two models. Thus, future research on caregiving hours for IADL is warranted to provide additional evidence. Nevertheless, caregiver hours with respect to BADL and IADL was a nonsignificant mediator between neuropsychiatric behaviors and caregiver burden. While it is not possible to change the deterioration of

Table 3
Caregiving hours for basic activities of daily living (BADL), instrumental activities of daily living (IADL) and caregiver burden in linear mixed-effects models accounting for repeated measures.

	Coefficient (SE)					
	DV: Caregiving hours for BADL[a]		DV: Caregiving hours for IADL[a]		DV: Caregiver burden[a]	
	Model 1	Model 2	Model 3	Model 4	Model 5	Model 6
Caregiving hours for BADL[a]	–	–	–	–	1.594 (0.389) **	1.339 (0.383) **
Caregiving hours for IADL[a]	–	–	–	–	1.135 (0.281) **	0.981 (0.267) **
Neuropsychiatric Inventory[a]	–	0.016 (0.004) **	–	0.010 (0.005) *	–	0.151 (0.027) **
Barthel Index score[a]	−0.011 (0.003)**	–	0.007 (0.003) *	–	−0.012 (0.019)	–
PWD age	−0.009 (0.010)	−0.003 (0.010)	0.020 (0.012)	0.017 (0.012)	−0.093 (0.081)	−0.090 (0.078)
PWD sex (Ref: female)	0.286 (0.190)	0.260 (0.182)	0.128 (0.219)	−0.219 (0.219)	−0.064 (1.543)	0.525 (1.473)
PWD severity	0.242 (0.114)*	0.371 (0.099**	0.101 (0.134)	−0.070 (0.119)	1.132 (0.913)	1.166 (1.550)
Caregiver sex (Ref: female)	−0.178 (0.198)	−0.067 (0.191)	−0.928 (0.228) **	−0.826 (0.229) **	0.918 (1.623)	1.676 (1.550)
Caregiver age	0.002 (0.008)	0.037 (0.008)	0.016 (0.010)	0.018 (0.010)	−0.091 (0.068)	−0.066 (0.065)
Caregiver education (Ref: ≤ junior high)	0.123 (0.213)	0.162 (0.205)	0.138 (0.245)	0.071 (0.246)	3.471 (1.727)	3.205 (1.652)
Caregiver marital status (Ref: married)	−0.099 (0.263)	−0.202 (0.251)	−0.108 (0.241)	−0.007 (0.301)	−2.032 (2.125)	−1.886 (2.020)
Duration in caregiving	−0.001 (0.002)	−0.0003 (0.002)	−0.003 (0.002)	−0.001 (0.002)	0.006 (0.016)	0.007 (0.015)
Living status (Ref: separated)	0.338 (0.210)	0.269 (0.203)	1.082 (0.241) **	0.983 (0.243) **	1.866 (1.723)	1.496 (1.649)
Good economic status (Ref: fair)	−0.329 (0.198)	−0.338 (0.190)	−0.407 (0.228)	−0.295 (0.227)	−1.975 (1.607)	−1.749 (1.532)
Poor economic status (Ref: fair)	−0.049 (0.204)	−0.116 (0.195)	0.269 (0.234)	0.267 (0.234)	4.971 (1.650) **	4.683 (1.578) **

DV = dependent variable.

Models 1 and 3 did not include caregiving hours for BADL, caregiving hours for IADL, and Neuropsychiatric Inventory score; Models 2 and 4 did not include caregiving hours for BADL, caregiving hours for IADL, and Barthel Index score; Models 5 and 6 did not include Neuropsychiatric Inventory and Barthel Index scores, respectively.

[a] These variable scores were treated as time-variant factors in the linear mixed-effects models.

* $p < 0.05$.

** $p < 0.01$.

Table 4
Result comparisons between regression and linear mixed-effects models.

Model #	Key findings from regression model	Key findings from liner mixed-effects model	Comparisons
Model 1	Barthel Index score significantly predicted caregiving hours for BADL	Barthel Index score significantly predicted caregiving hours for BADL	Same
Model 2	Neuropsychiatric Inventory significantly predicted caregiving hours for BADL	Neuropsychiatric Inventory significantly predicted caregiving hours for BADL	Same
Model 3	Barthel Index score significantly predicted caregiving hours for IADL	Barthel Index score significantly predicted caregiving hours for IADL	Same
Model 4	Neuropsychiatric Inventory **did not** significantly predict caregiving hours for IADL	Neuropsychiatric Inventory significantly predicted caregiving hours for IADL	Different
Model 5	Caregiving hours for BADL and IADL both significantly predict caregiver burden	Caregiving hours for BADL and IADL both significantly predict caregiver burden	Same
Model 6	Caregiving hours for BADL and Neuropsychiatric Inventory both significantly predict caregiver burden. Caregiving hours for IADL **did not** predict caregiver burden	Caregiving hours for BADL and IADL and Neuropsychiatric Inventory all significantly predict caregiver burden	Different in caregiving hours for IADL

BADL = basic activities of daily living; IADL = instrumental activities of daily living.

PWDs' BADL function, our finding of caregiving hours in BADL as a mediator suggest that providing respite care hours to assist with PWD's BADL function could also reduce caregiver burden.

One interesting finding is that the caregiving hours in BADL performed differently than the caregiving hours in IADL when we tested the association between PWD's BADL function and caregiver burden. One reason why caregiving hours in IADL was not a mediator might be because we did not examine the IADL function of the PWD. Some might argue that the mediating effects of caregiving hours in IADL would exist if we had used IADL function instead of BADL in our regression models. However, because the BADL function was relatively low in our PWD (moderate dependency at baseline [BI score = 75.08] and near-severe dependency in the follow-up [BI score = 63.67] (Shah, Vanclay, & Cooper, 1989)), we speculated that almost all of our PWD had similarly low IADL functions since IADL is more difficult to perform than BADL (Jekel et al., 2015). In this sense, we postulated that our results would be similar to those had we used IADL function in the regression models. Another explanation for the different results between caregiving hours in BADL and IADL is that caring for a PWD's BADL is more exhaustive and disconcerting than caring the PWD's IADL. For example, caring for bowel movements and bladder functions in BADL may make caregivers feel uncomfortable, while transferring and bathing in BADL may physically tire caregivers more than tasks in IADL, such as shopping.

The strengths of this study include the longitudinal design, a relatively large sample, and the information derived from both the caregivers and PWD. Moreover, studies involving older populations are under-represented because recruiting and maintaining older people in a longitudinal study is particularly difficult. Thus, studies of older populations often have lower enrollment and higher drop-out rates (Cherubini & Gasperini, 2017). Nevertheless, we were able to maintain the number of participants at nearly 200 in this longitudinal study. Given that the original SPM is quite complex, caregivers need to complete many questionnaires to help researchers collect needed variables. In response, we proposed a simplified SPM so that future studies could use a simpler model to lessen the response burden for caregivers.

There are some limitations in our study. First, all participants were community-dwelling PWD recruited from one teaching hospital in southern Taiwan; as such, the generalizability of our study results is limited. Second, 72% of our sample had mild or moderate dementia, so those in the severe stage were under-represented. We also could not analyze PWD according to different types of dementia since most of our sample were diagnosed with Alzheimer's disease. In order to detect effects of attrition bias due to the 35% dropped-out rate, we conducted chi-squared homogeneity tests of baseline characteristics among the complete cases and drop-outs, and found that both caregivers and PWD were younger in age among study drop-outs. However, since the two groups did not have any significant difference in BI or NPI scores, our main findings regarding caregiving hours in BADL might not have changed. Second, although we conducted a longitudinal study to test the temporal association between PWD characteristics, caregiving hours, and caregiver burden, we cannot claim causal relationships since both caregiving hours and caregiver burden were collected during the same interview. Future studies could consider using a longitudinal design with several repeated measurement points and cross-lagged analysis to examine whether decreasing caregiving hours can alleviate the caregiver burden to obtain causal effect estimates. Third, we did not define 'providing care' in this study, and the caring hours varied among our participants. Specifically, a few caregivers consider that they were providing care and but spent little time on basic/instrumental ADL (e.g., 1 h or less per week). It may be interesting to compare our results which used a subjective assessment of caregiving with future studies that used caregiving hours to define caregivers to see their findings would differ.

5. Conclusion

In conclusion, our results partially support the simplified SPM: caregiving hours in BADL mediated the relationship between BADL function of PWD and caregiver burden. However, such mediating effects were not found in the relationship between neuropsychiatric

Table 5
Mediated effects of caregiving hours in association with the Barthel Index score (or Neuropsychiatric Inventory score) and caregiver burden.

	Mediator					
	Caregiving hours for BADL[a]			Caregiving hours for IADL[a]		
	Effect	SE[b]	95% CI[b]	Effect	SE[b]	95% CI[b]
Barthel Index[a]	−0.0137	0.0095	(-0.0379, -0.0003)	0.0100	0.0078	(-0.0004, 0.0315)
Neuropsychiatric Inventory[a]	0.0150	0.0120	(-0.0015, 0.0475)	0.0045	0.0076	(-0.0039, 0.0291)

BADL = basic activities of daily living; IADL = instrumental activities of daily living.

[a] These variable scores represent *changed performance* because they were calculated using wave 2 scores minus wave 1 scores.

[b] SE and 95% CI were calculated using bootstrapping methods with 5000 repeated samples.

behaviors of PWD and caregiver burden. Moreover, caregiving hours in IADL was not a mediator in our simplified SPM. Thus, healthcare professionals may consider placing more emphasis on assisting with BADL when designing a respite care service for informal caregivers.

Declarations of interest

None.

Acknowledgement

Data collection of this work was supported by the Ministry of Science and Technology (MOST 102-2410-H-006-001-SS2 and MOST 104-2410-H-006-101) of Taiwan.

References

American Psychiatric Association (1994). *Diagnostic and statistical manual of mental disorders* (5th ed.). .

Atlantis, E., Browning, C., & Kendig, H. (2010). Body mass index and unintentional weight change associated with all-cause mortality in older Australians: The Melbourne Longitudinal Studies on Healthy Ageing (MELSHA). *Age and Ageing, 39*, 643–646.

Bergvall, N., Brinck, P., Eek, D., Gustavsson, A., Wimo, A., Winblad, B., ... Jönsson, L. (2011). Relative importance of patient disease indicators on informal care and caregiver burden in Alzheimer’s disease. *International Psychogeriatrics, 23*, 73–85.

Bureau of National Health Insurance (2013). *Reimbursement rule of drugs acting on the nervous system.* Taiwan.

Chang, C.-C., Su, J.-A., & Lin, C.-Y. (2016). Using the Affiliate Stigma Scale with caregivers of people with dementia: Psychometric evaluation. *Alzheimer's Research & Therapy, 8*, 45.

Chappell, N. L., & Reid, R. C. (2002). Burden and well-being among caregivers: Examining the distinction. *The Gerontologist, 42*, 772–780.

Cherubini, A., & Gasperini, B. (2017). How to increase the participation of older subjects in research: Good practices and more evidence are needed!. *Age and Ageing,* 1–2.

Cummings, J. L. (1994). The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology, 44*, 2308.

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). “Mini-mental state”: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*, 189–198.

Giovannetti, T., Thomas, D., & Marcotte, I. (2010). Neuropsychology of everyday functioning. *Journal of the International Neuropsychological Society: JINS, 16*, 946.

Hsueh, I. P. (2001). Psychometric characteristics of the Barthel activities of daily living index in stroke patients. *Journal of the Formosan Medical Association, 100*, 526.

Hughes, C. P., Berg, L., Danziger, W. L., Coben, L. A., & Martin, R. L. (1982). A new clinical scale for the staging of dementia. *The British Journal of Psychiatry, 140*, 566–572.

Jekel, K., Damian, M., Wattmo, C., Hausner, L., Bullock, R., Connelly, P. J., ... Graessel, E. (2015). Mild cognitive impairment and deficits in instrumental activities of daily living: A systematic review. *Alzheimer's Research & Therapy, 7*, 17.

Kim, H., Chang, M., Rose, K., & Kim, S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing, 68*, 846–855.

Ku, L.-J. E. (2016). Economic impact of dementia by disease severity: Exploring the relationship between stage of dementia and cost of care in Taiwan. *PloS One, 11*, e0148779.

Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist, 9*, 179–186.

Li, H., Jia, J., & Yang, Z. (2016). Mini-mental state examination in elderly Chinese: A population-based normative study. *Journal of Alzheimers Disease, 53*, 487–496.

Lin, C.-Y., Ku, L.-J. E., & Pakpour, A. H. (2017). Measurement invariance across educational levels and gender in 12-item Zarit Burden Interview (ZBI) on caregivers of people with dementia. *International Psychogeriatrics,* 1–8.

Lin, C.-Y., & Tsai, M.-C. (2016). Effects of family context on adolescents’ psychological problems: Moderated by pubertal timing, and mediated by self-esteem and interpersonal relationships. *Applied Research in Quality of Life, 11*, 907–923.

Lin, C.-Y., Wang, J.-D., Pai, M.-C., & Ku, L.-J. E. (2017). Measuring burden in dementia caregivers: Confirmatory factor analysis for short forms of the Zarit Burden interview. *Archives of Gerontology and Geriatrics, 68*, 8–13.

Lyketsos, C. G., Carrillo, M. C., Ryan, J. M., Khachaturian, A. S., Trzepacz, P., Amatniek, J., ... Miller, D. S. (2011). *Neuropsychiatric symptoms in Alzheimer’s disease.* Elsevier.

Mahoney, F. I., & Barthel, D. W. (1965). Functional evaluation: The barthel index. *The Maryland State Medical Journal, 930*, 1461–1465.

Montoya, A. K., & Hayes, A. F. (2017). Two-condition within-participant statistical mediation analysis: A path-analytic framework. *Psychological Methods, 22*, 6.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*, 583–594.

Preacher, K. J., & Hayes, A. F. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behavior Research Methods, 36*, 717–731.

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: A systematic review and metaanalysis. *Alzheimer’s & Dementia, 9*, 63–75 e62.

Schreiner, A. S., Morimoto, T., Arai, Y., & Zarit, S. (2006). Assessing family caregiver’s mental health using a statistically derived cut-off score for the Zarit Burden Interview. *Aging & Mental Health, 10*, 107–111.

Shah, S., Vanclay, F., & Cooper, B. (1989). Improving the sensitivity of the Barthel Index for stroke rehabilitation. *Journal of Clinical Epidemiology, 42*, 703–709.

van der Lee, J., Bakker, T. J., Duivenvoorden, H. J., & Dröes, R.-M. (2014). Multivariate models of subjective caregiver burden in dementia: A systematic review. *Ageing Research Reviews, 15*, 76–93.

Varela, G., Varona, L., Anderson, K., & Sansoni, J. (2011). Alzheimer’s care at home: A focus on caregivers strain. *Professioni Infermieristiche, 64*, 113.

Wimo, A., Gustavsson, A., Jönsson, L., Winblad, B., Hsu, M.-A., & Gannon, B. (2013). Application of Resource Utilization in Dementia (RUD) instrument in a global setting. *Alzheimer’s & Dementia: The Journal of The Alzheimer’s Association, 9*, 429–435 e417.

Yates, M. E., Tennstedt, S., & Chang, B.-H. (1999). Contributors to and mediators of psychological well-being for informal caregivers. *The Journals of Gerontology Series B, Psychological Sciences and Social Sciences, 54*, P12–P22.